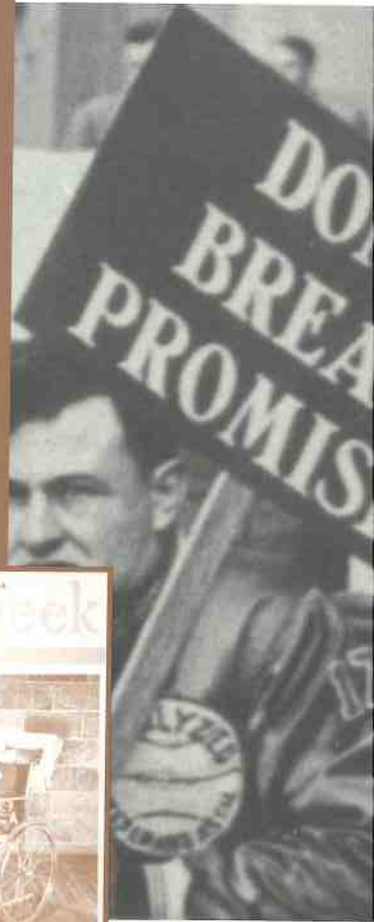




PARALYZED VETERANS OF AMERICA



*Building
a Better
America*





PARALYZED VETERANS OF AMERICA


Mission Statement



The Paralyzed Veterans of America, a congressionally chartered veterans service organization founded in 1946, has developed a unique expertise on a wide variety of issues involving the special needs of our members—veterans of the armed forces who have experienced spinal cord injury or dysfunction.

PVA will use that expertise to be the leading advocate for:

- Quality health care for our members,
- Research and education addressing spinal cord injury and dysfunction,
- Benefits available as a result of our members' military service,
- Civil rights and opportunities which maximize the independence of our members.

To enable PVA to continue to honor this commitment, we must recruit and retain members who have the experience, energy, dedication, and passion necessary to manage the organization and ensure adequate resources to sustain the programs essential for PVA to achieve its mission. 



Serving Our Veterans

Since its founding 60 years ago, the Paralyzed Veterans of America has never wavered in its mission of service to our nation's veterans who have spinal cord injury (SCI) or dysfunction.



Randy L. Pleva, PVA national president

Back in PVA's formative years, "paraplegia" wasn't a word most people knew. The public never saw a person on the street in a wheelchair. And nobody quite knew what to do with the hundreds of men paralyzed in World War II. America certainly wasn't ready for them. They were essentially warehoused around the country in specialized hospitals: 200 paraplegics at Birmingham near Los Angeles, 300 in Atlantic City, 100 in Boston, and so on. The seeds of PVA were sewn as these men saw strength in numbers, that the group is stronger than the sum of its individuals, and that as a group they could bring about change.

War heroes, yes, but our founding fathers were just as surely heroes after their service. These men were visionaries who not only sought to achieve immediate improvement in the plight of veterans with SCI, but realized the value of legislative advocacy, a commitment to research for a cure, and programs to reintegrate these men and women into society. They understood as well that what they could achieve on behalf of paralyzed veterans would ultimately improve the lives of anyone with SCI.

I wish I could go back in time and visit with some of the guys who first formed the chapters that became the Paralyzed Veterans of America. I wish

I could sit with Fred Smead, the California paraplegic who in 1946 testified before Congress to increase compensation for paralyzed vets. I'd like to visit with the first PVA president, Gil Moss, who was from the Chicago area. I'd like to talk to these men and some of the other pioneers about their lives, their sacrifices, their hopes for the future, their determination. I'd like to talk about our shared experiences with paralysis. I'd like to talk about what their goals were, and I'd like them to see how far we've come toward those goals today.

As it was for these men, PVA was enormously empowering for me. After serving in Vietnam for 13 months, I came home to work in the coal mines in West Virginia. A mine accident left me paralyzed. I learned how to get around and deal with my new life on wheels from people in the community. I'd never heard of PVA, but once I had used up my own resources—bought my own wheelchairs and equipment—someone told me about the vet center, and that's where I first heard about PVA.

There was no chapter in West Virginia so I contacted the Kentucky-Indiana chapter to ask if there was any way I could help them out. Turns out they were the ones who helped me. They opened my eyes to a world of benefits and services. I eventually helped start a chapter in West Virginia and

later on became more involved in national PVA. Serving as president during the 60th year of the organization has certainly been a highlight for me, but seeing our victories on behalf of the spinal cord injured means so much more.

The goals of the Paralyzed Veterans of America today are much the same as they were back in 1946: We join our voices to make sure veterans with spinal cord injury or disease have access to the best medical care. We want them to live in their communities and participate to the fullest degree they desire. And we want this not only for veterans but for all citizens with disabilities.



(left to right) Gregory P. Bacopulos, president, Mid-South PVA; Frank DeGeorge, national president, PVA; Kenneth Jackson, Vietnam veteran; and Marx E. Campbell, vice president, Mid-South PVA—September 18, 1973.

Sure, you can look back and say that over 60 years we've come a long way. We have 34 chapters and many more service offices to make sure today's spinal cord injured vets get taken care of and get the benefits to which they are entitled. We have 24 VA hospitals that specialize in spinal cord injury. We support a world-class scientific research effort, and we have an outstanding record in providing

education and training materials to the public and to professionals in health care. In the following pages, you will learn about many of our achievements since those first brave groups of veterans pulled together 60 years ago to fight for the spinal cord injured.

But there is still work to do. We need to keep our issues in front of the public. People listen when you wheel in. I don't know how else to put this, but the wheelchairs do a lot of talking for us. It was a big plus back in the early days and it is even today. Even though the Americans with Disabilities Act was passed 16 years ago, there are still courthouses and voting

booths that are not accessible. There are veterans in rural areas who do not get the medical care they deserve. There are far too many people with disabilities who are unable to find jobs, even though they are qualified. There is much more work to do, and we, as members of PVA, accept the challenge and will continue to work hard to maintain this important legacy.

Sixty years—that's a long time in the life of an organization. It gives us a great opportunity to reflect on where we've been and how we got where we are,

and, of course, to renew our vision of where we are going.

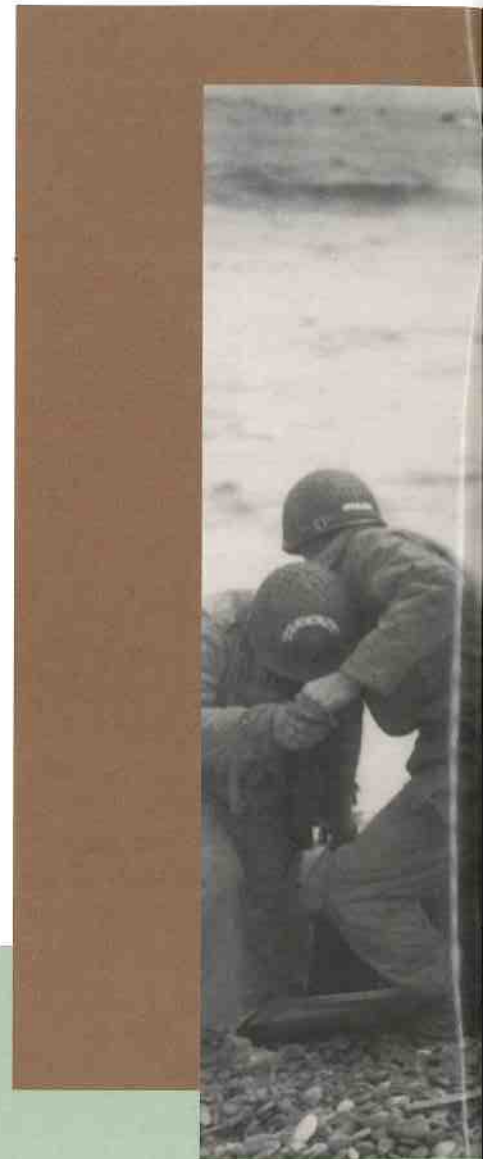
Randy L. Pleva, Sr.
PVA National President

Birth of an Organization

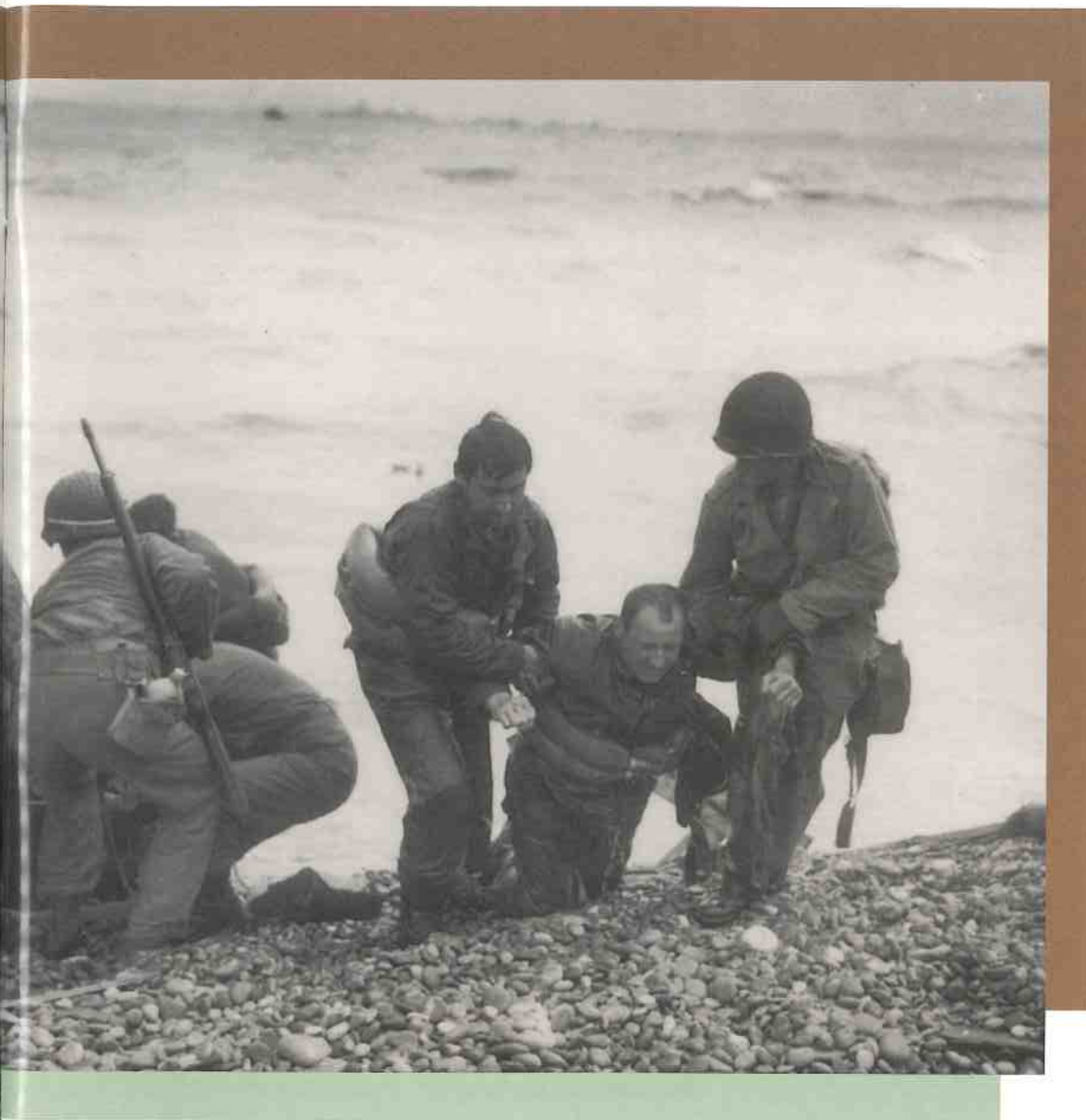
Veterans who suffered spinal cord injury during World War II faced a country unprepared to deal with them or their needs. These paralyzed veterans presented the medical profession with many new challenges. The first problem: keeping them alive. Though the advent of antibiotics was critical to initial survival of an SCI veteran, the secondary conditions that paralysis caused, such as pressure sores and urinary conditions, meant long-term and specialized care. Hospitalization averaged two-and-a-half to five years.



Veterans returning home with spinal cord injuries sustained in battle during World War II soon had an organization dedicated to their needs—the Paralyzed Veterans of America.



"I had not heard the term 'paraplegic' during my two-and-a-half years of surgical training or six months in neurosurgery," Dr. Robert Heimburger of the Mayo General Hospital in Galesburg, IL, recalled. "At that time SCI meant sure death in about 12 months. Fortunately, the medical corpsmen and nurses knew the [recovery] routine, and I became familiar with the many problems that result from SCI and something about what could be done to help relieve them."



Advances in Medical Care

Dr. Heimburger, along with Dr. L. W. (Bill) Freeman, made many advances in the care and treatment of servicemen with SCI. "Along with corpsmen and nurses, we doctors became experts in regulating the siphoning devices to train paralyzed bladders to empty on demand, rather than randomly or not at all," Dr. Heimburger said. "Every-two-hour turning was routine, whether on a Stryker frame or in a bed, and helped prevent decubiti [pressure ulcers].

"Freeman and I spent many hours in the operating rooms. A few paraplegics were treated with decompressive laminectomies (removing bone to give the compressed spinal cord more room) in the hope of providing a little more muscle function, with some success. Return of the ability to move a paralyzed thumb in men with neck injuries or a few leg muscles in those with lower SCI were real triumphs."

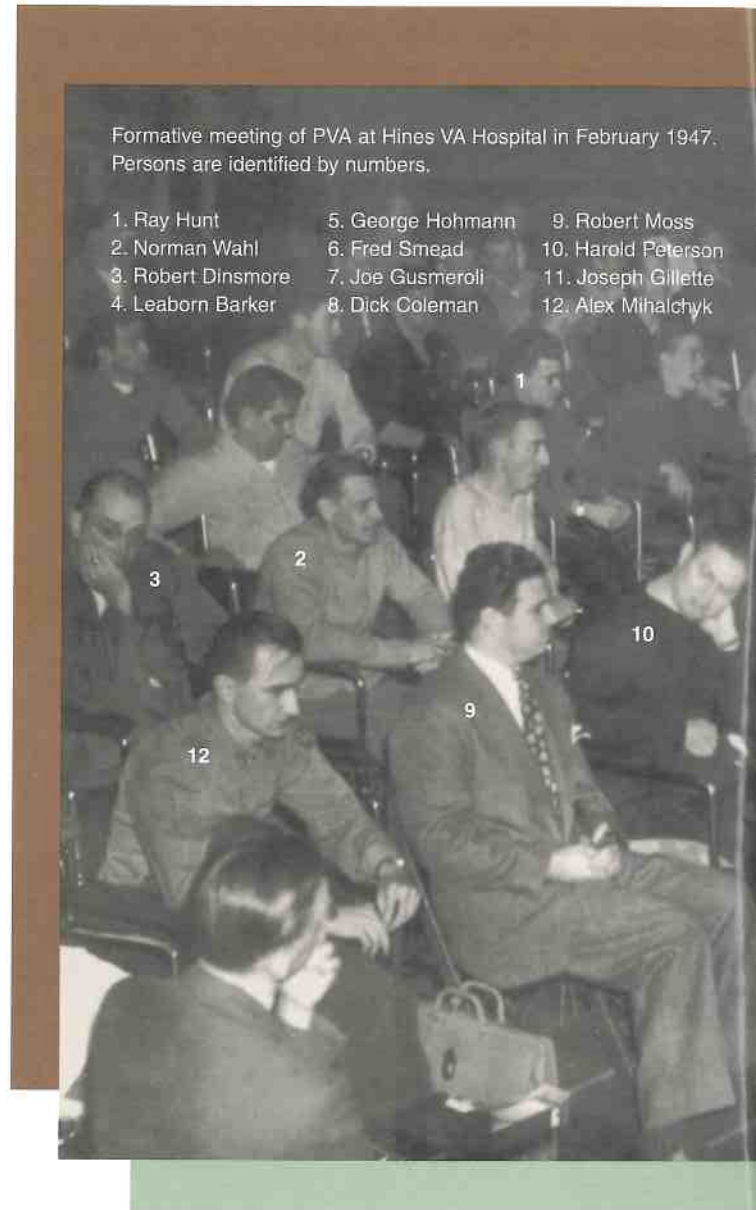
Physical therapy, not as well established for paraplegia as for other disorders, was developed by Freeman in consultation with skilled therapists, nurses, and corpsmen. The monstrous wooden wheelchairs available at the time were replaced by sturdy but lightweight collapsible models, developed through the collaboration of imaginative manufacturers, paraplegic patients, therapists, Freeman, and other doctors. Patients became skilled, nimble, and quick in wheelchairs as they built up their shoulders, arms, and hands to take over for their paralyzed legs.

But doctors like Heimbürger and Freeman were the exception rather than the norm. The care received by many SCI veterans at military or VA hospitals was at a minimum inadequate—in some cases practically nonexistent—because many medical professionals thought nothing could be done but keep them alive for a time. However, the founding fathers of the Paralyzed Veterans of America refused to accept this notion, and paralyzed veterans began to form associations at hospitals and medical centers around the country.

Founding member George W. Hohmann, PhD, was a patient at Bushnell Army Hospital in late 1944. He recalled during the organization's oral history project: "We had developed... a good deal of camaraderie and friendship amongst ourselves, and mutual support. (We) felt very strongly that it was important to maintain association with other people who had similar types of problems... we decided that we should put together an organization for spinal cord injured individuals...."

The Nucleus

In January 1946, 70 paraplegic patients at Birmingham General Hospital in California, along with emissaries from Bushnell, decided to "found the nucleus of an organization to safeguard the interests of all paraplegic patients in the nation," reported the group's medical adviser, Dr. Ernest Bors, to the hospital's commanding officer. "The patients request permission to send, through

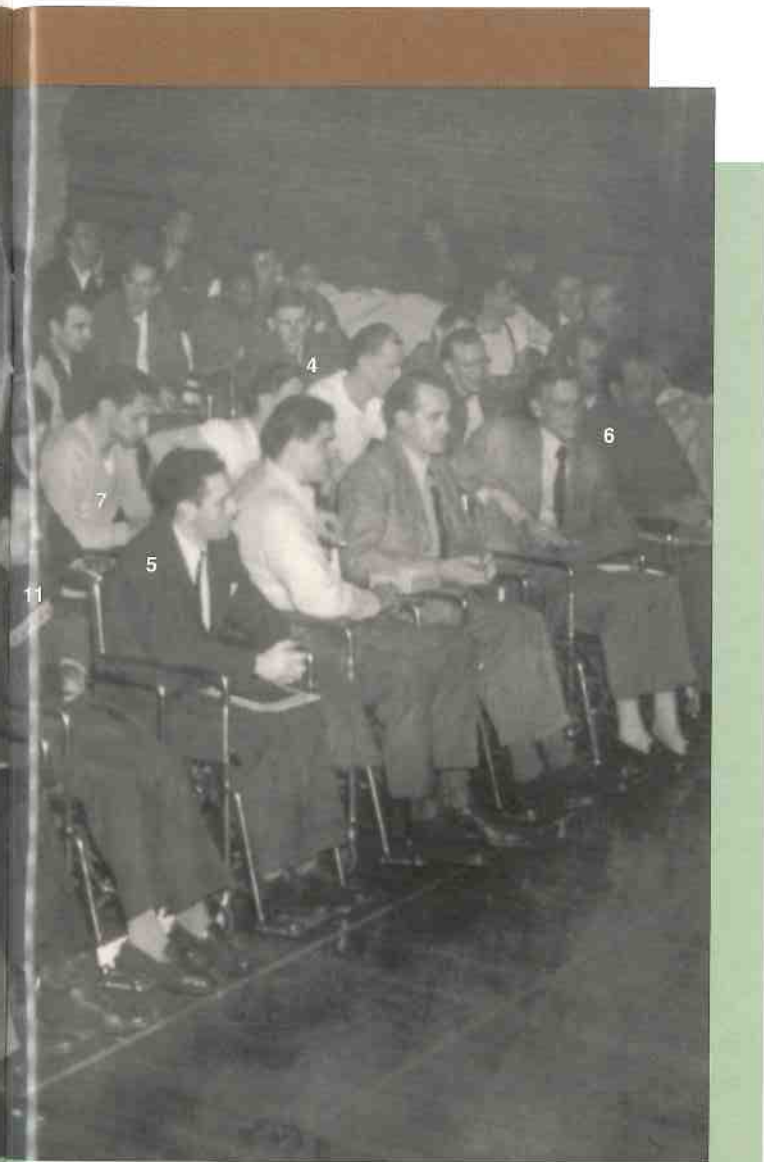


Formative meeting of PVA at Hines VA Hospital in February 1947. Persons are identified by numbers.

- | | | |
|--------------------|-------------------|---------------------|
| 1. Ray Hunt | 5. George Hohmann | 9. Robert Moss |
| 2. Norman Wahl | 6. Fred Smead | 10. Harold Peterson |
| 3. Robert Dinsmore | 7. Joe Gusmeroli | 11. Joseph Gillette |
| 4. Leaborn Barker | 8. Dick Coleman | 12. Alex Mihalchyk |

channels, all matters pertaining to the new organization to all paraplegic patients in other paraplegic centers of the nation."

The Paralyzed Veterans Association at Birmingham General Hospital was chartered by the state of California in March and began to spread the word among other paraplegic centers of the need for organization at the hospital level. Veterans at Halloran hospital in New York organized in May. Bronx and St. Albans groups formed shortly thereafter. Concurrently, veterans also were organizing



in other areas of the country until there were nine such groups in the United States.

In July 1946, SCI patients in the Bronx VA Hospital published the four pages comprising the first issue of *The Paraplegia News (PN)*. It was hoped that the publication would serve as "a medium for the exchange of ideas among SCI patients, as a challenge to doctors to continue providing good medical care, and as a form of entertainment for those others contributing to patient welfare."

The Bronx organization put forth the following aims: "The purpose of the Paralyzed Veterans Association is to advocate and foster thorough and continuing medical research in the several fields connected with injuries and diseases of the spinal cord...we advocate [a] complete and effective reconditioning program...we advocate legislation permitting the hiring of an attendant by the Veterans Administration for the veteran who is so disabled that he cannot otherwise remain away from the hospital...we hope that by publicizing our needs we will be able measurably to lessen the plight of civilian paraplegics...." Funds were sought to carry out these aims and to move forward in forming a national organization.

In February 1947, delegates from seven of the nine paralyzed veterans' groups met in Hines VA Hospital's Vaughan Unit for the first "convention" of the Paralyzed Veterans Associations of America (PVAA). Conditions and treatments for veterans with SCI were about to change.



The Paraplegia News (PN) was first published in July 1946 by SCI patients in the Bronx VA Hospital.

Delegates worked into the night, drawing up articles of incorporation and bylaws. On February 9, they framed four resolutions, calling for the following:

- legislation to increase the automobile allowance to veterans with paraplegia;
- formation of a housing committee;
- provision of VA housing for physical therapists; and
- formation of a research committee.

Gilford Moss (Vaughan) was elected national chairman; each chapter would appoint two representatives to the board of directors. The new organization would be headquartered in Cook County, IL.

The organization's purpose, as outlined in the new articles of incorporation, was:

- (1) to form a national association for the benefit of people with SCI;
- (2) to help constituent associations in carrying on educational programs and procuring benefits for members;
- (3) to act for and on behalf of constituent associations;
- (4) to promote medical research in the fields connected with SCI;
- (5) to advocate and foster complete rehab programs for members and other people with SCI; and
- (6) to publicize the organization's objectives and take the necessary action to accomplish them.

Specific actions urged at this convention included creation of domiciliary care for the nonservice-connected in the VA hospital system; liberalization of the auto grant to include eligibility for quadriplegics; and the creation of a spinal cord research foundation. In the months that followed, a considerable amount of work was



Early flag of the Paralyzed Veterans of America.

done. Members testified on Capitol Hill on the auto and housing bills. Moss took actions to establish a research program. The Paralyzed Veterans Associations of America was moving forward.

At the second convention (September 1947), a Committee on National Legislation was formed to report to members the progress of congressional legislation affecting paralyzed

veterans. Delegates agreed to urge VA hospitals to guarantee bed space for domiciliary care of individuals with SCI. They also planned to draft a letter to Gen. Omar Bradley, the first chairman of the Joint Chiefs of Staff, suggesting that the Veterans Administration authorize Paralyzed Veterans Associations of America and affiliated chapters to handle the problems of veterans with SCI. In addition, it was resolved that a board of trustees would be elected to raise funds to be allocated to the National Research Council for research in paraplegia.

Growth

Early in 1948, the national association completed a voluntary trust agreement for the formation of the Paralyzed Veterans Research Foundation. A later meeting led to the establishment of the National Paraplegia Foundation (NPF), a strong indication of the Paralyzed Veterans of America's commitment to SCI research.

But at the convention that year, Moss reported some setbacks: Among other denials, VA had rejected or refused requests by PVAA to recognize it as representative for claims of members, to support paraplegic housing, to advise field offices on prosthetic equipment for paraplegics, and to permit SCI personnel to visit other SCI centers to broaden their knowledge. One step forward, two steps back, it seemed.

Funding, control over NPF, standardization of rules for wheelchair sports, and the organization's legislative agenda were other topics of discussion at that third meeting. The name of the organization was officially changed to Paralyzed Veterans of America (PVA). *PN* reported, "There were differences of opinion, and some were settled by close votes, but the decision of the vote was the decision of all. Probably for the first time, we have become a national organization in the full sense of the word."

Victory was attained with the passage of P.L. 702 (the Paraplegic Housing Bill), which entitled veterans with SCI to "assistance in acquiring a suitable housing unit with special fixtures or movable facilities made necessary by the nature of the person's disability." But an unexpected disappointment came after the 1948 convention when President Harry Truman vetoed a bill that would have provided \$1,600 toward the purchase of an automobile for "seriously disabled" World War I and II veterans. The organization had spent two years campaigning for this benefit.

Growing Pains

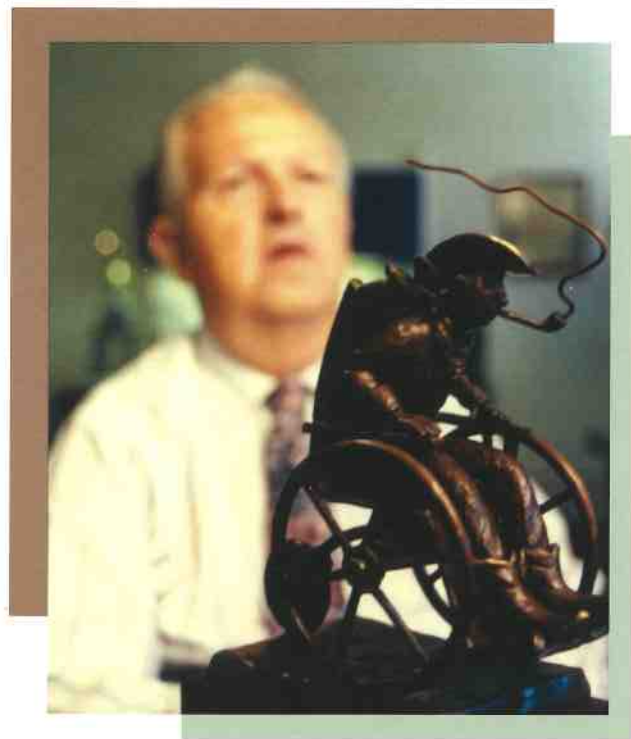
PVA felt dramatic changes in the following years, particularly in 1950. At convention, the primary topic of discussion was the need for and the cost of maintaining a national organization. As a result, delegates voted to dissolve national headquarters in New York and abolish the position of executive secretary. The reason for the decision, as reported in *PN*, was "a strong, sincere desire on the part of the delegates and the chapters they represented to promote basic medical research in the various fields connected with paraplegia."

In the following year all activities were eliminated, with the exception of publishing *PN*. At the convention, a resolution was made to abolish the national organization—but this was defeated. The predominant feeling was that a strong organization was needed and wanted.



Boosted by a strong legislative program in the next few years, the Paralyzed Veterans of America began to regain strength. New chapters came aboard. "Speedy" was endorsed in 1958 as the organization's national emblem, symbolic of energy, drive, happiness, admiration, and guts. Most important, however, a fundraising program was begun, which has ensured PVA's continued viability and the expansion of its programs and services over the years. In 1964, headquarters were moved from New York to Washington, DC, to strengthen the veterans voice on Capitol Hill.

In 1971, its 25th year, the Paralyzed Veterans of America received a congressional charter as a nonprofit national veterans service organization. Today it is the only congressionally chartered veterans service organization dedicated solely to the benefit and representation of veterans



"Speedy" was endorsed in 1958 as the organization's national emblem, symbolic of energy, drive, happiness, admiration, and guts. Dick Sloviachek is considered to have been the veteran on whom Speedy was based.




R. Jack Powell, executive director (left), and Mike Delaney, president, at the 1981 ground-breaking ceremony for PVA's Washington, DC, headquarters.

with spinal cord injury or disease. This specialized expertise ultimately effects change for the entire disability community as well.

Expansion of the fundraising program has meant a dramatic increase in size and scope of the programs and services over the past 35 years. Today PVA has 34 chapters and 60 service offices in the United States and Puerto Rico, directly serving approximately 20,000 paralyzed veterans and their families—and offering assistance to hundreds of thousands of veterans in general. Since the establishment of a research program in 1975, millions of dollars have been awarded for research and education into spinal cord injury or dysfunction (SCI/D) care and the search for a cure. A strong legislative focus has not only brought about significant laws, such as the Veterans Health Care Eligibility Act, but helps to ensure adequate funding for veterans health care. Expanded sports and recreation programs provide opportunities in a broad range of activities that help get veterans back into an active lifestyle.

PVA Presidents

Gilford Moss, 1947
 Robert Moss, 1948
 Bernard Shufelt, 1948–1949
 Patterson Grissom, 1950
 Stanley Reese, 1951
 William Green, 1952–1953
 Robert Frost, 1954–1955
 Raymond Conley, 1956–1957
 Harry A. Schweikert, Jr., 1958
 Dwight Guilfoil, 1959
 Robert Classon, 1960–1961
 John Farkas, 1962–1963
 Harold Stone, 1964
 Harold W. Wagner, 1964–1965
 Leslie P. Burghoff, 1966–1967
 Wayne L. Capson, 1968–1969
 Carlos Rodriguez, 1970–1971
 Frank DeGeorge, 1972–1973
 Donald Broderick, 1974–1975
 Edward Jasper, 1976–1977
 Joseph Romagnano, 1978–1979
 Michael Delaney, 1980–1981
 Paul Cheremeta, 1982–1983
 Richard D. Hoover, 1984–1986
 Jack Michaels, 1987–1988
 F. David Parker, 1989
 Victor S. McCoy, Sr., 1990–1991
 Richard F. Johnson, 1992–1993
 Richard Grant, 1994–1995
 Kenneth Huber, 1996–1997
 Homer S. Townsend, Jr., 1998–2000
 Joseph L. Fox, Sr., 2001–2004
 Randy L. Pleva, Sr., 2005–present

“PVA is an organization that has endured many changes and challenges,” said Louis Irvin, acting deputy executive director. “The mission of PVA, to improve the quality of life for veterans with spinal cord injury or disease, is the driving force that has made the organization strong and motivated to continue.” 

CURTIS HOBBS

Curtis Hobbs, who turns 84 this year, participated in his fourth National Veterans Wheelchair Games in July. He learned about the Games through the Paralyzed Veterans of America, competing for the first time in 2003. He has won 11 medals, including three golds.

"I'm not as good as I used to be but I compete in nine ball, bowling, air guns, and ping pong," Hobbs said. "I used to bowl quite a lot, so that's really my favorite.



"I don't care if I get a medal or not. It's quite an adventure just making the trip and being around all the other competitors. There aren't too many my age, though."

Hobbs served in the Army Air Force in Guam during World War II. He reenlisted and was sent to Japan as part of the occupation force and then to Korea, as part of one of the first detachments. He was discharged in 1951 and returned to the States, where he became an electrician. In 1966, he fell down a flight of stairs.

"I broke my hip and injured my spinal cord. My life changed completely," he said.

"I was sent to Boston City Hospital. After six months I was sent to the VA hospital in Roxbury. There they had a lot of therapies City Hospital didn't.

"I couldn't feed myself—my injury was at C6 to C7. So I stayed in the VA hospital. I left in 1978. By this time I had recovered a lot—I had started walking."

While Hobbs was in the VA hospital, PVA was at his side. "They helped me a lot, making sure I got my benefits, making sure I got my health care. They helped me get some training so I could work—I made belts and watches. It was good to do something with my hands," he said.

After his discharge from the hospital, Hobbs got an apartment in Boston, where he has lived ever since. He worked soldering wires for telephones and small appliances.

"Because I have lived a long time, and because I have survived a tough injury, I get questions from moms and dads, from wives, about their loved one who got a spinal cord injury.

"The young guys—they don't believe that they can live. I tell them they need to learn as best as they can to take care of themselves. I tell them that to live a long and happy life, take some exercise, play sports, and have willpower.

"I tell them it's not easy but that there are others who have been through it and live good lives. I tell them about PVA. PVA has been very good to me. Whatever I don't know to tell them, PVA knows."

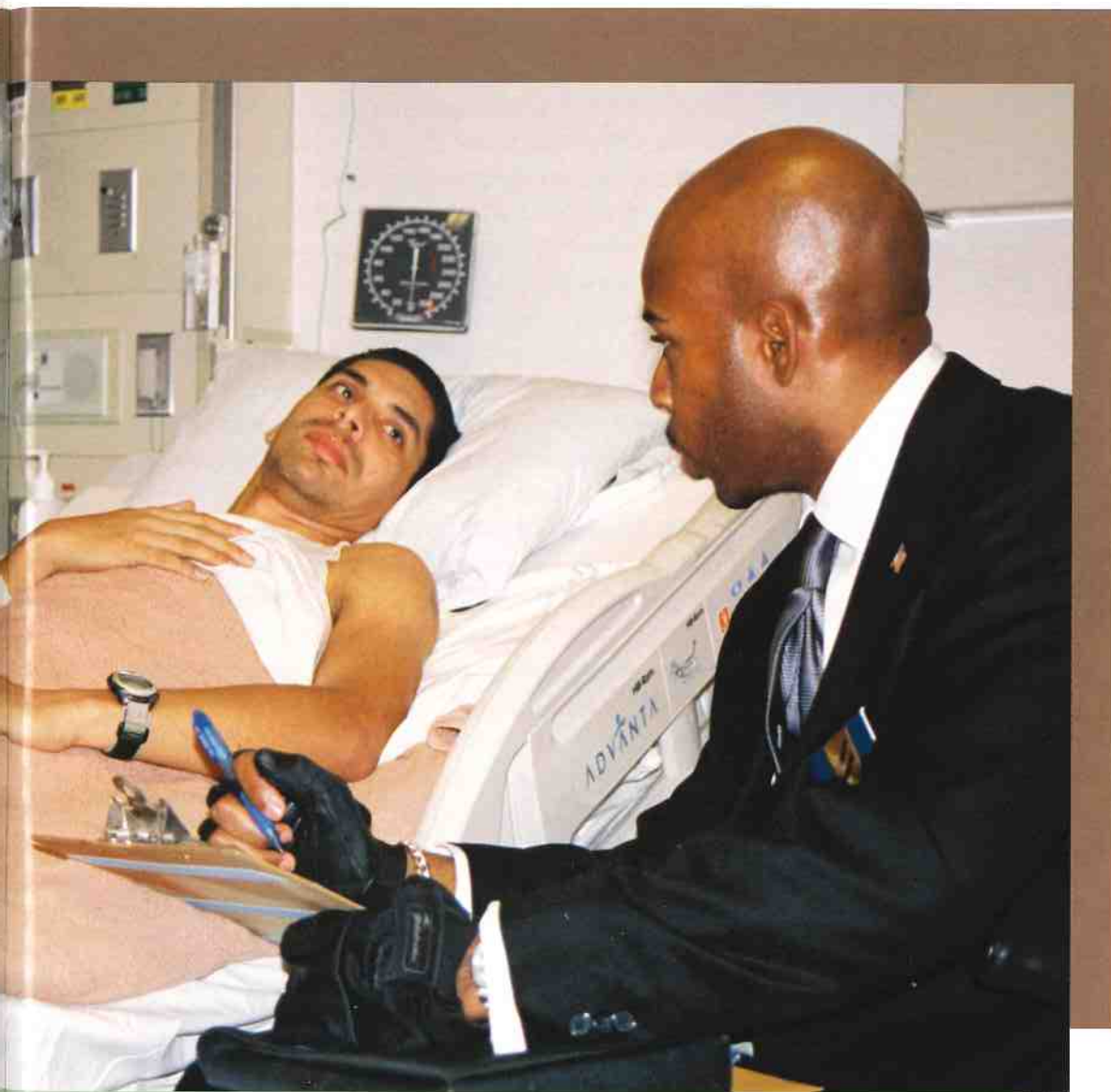
Service Is Our Mission

The founders of the Paralyzed Veterans of America believed that helping veterans secure the benefits and health care to which they were entitled was central to the organization's mission. To achieve that goal, a service program was formed in 1946—informally, as it were—with volunteers helping their fellow veterans learn the Veterans Administration (now Department of Veterans Affairs) system. However, because the Paralyzed Veterans of America wasn't congressionally chartered and therefore not recognized as a veterans service organization, its members did not have the accreditation needed to represent claimants.



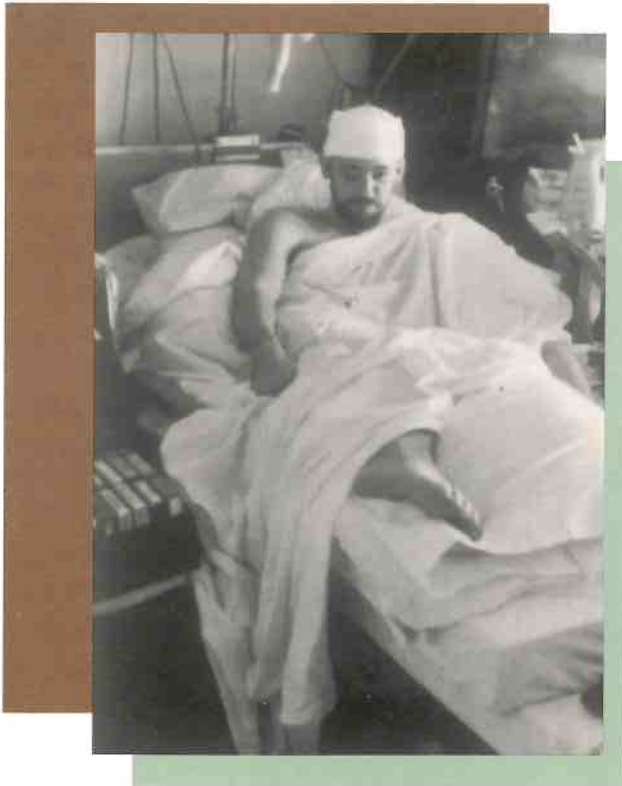
Yesterday and today—
being there for our
members. Pictured:
Sherman Gillums,
national service
officer II in San Diego

But chapters around the country continued to operate their own volunteer service programs, guiding their peers through the VA system, acquisition of benefits, and their rehabilitation. A concerted grass-roots lobbying effort impressed upon Congress the need for the charter, which would grant the Paralyzed Veterans of America the important status as an accredited veterans service organization. Receiving its congressional charter



in 1971, the Paralyzed Veterans of America finally had the right to have service officers accredited, enabling it to perform any duties necessary in representing members and other veterans. After receiving the charter, the members of the organization voted to establish a national service program. The first national service officer (NSO) seminar providing formal training took place in the Washington, DC, area shortly thereafter.

At the 1974 convention, it was decided that the service program be permanently moved to quarters inside VA, and the office opened a few months later. The next year, the Board of Directors decided the national service director should work out of the national office; insisted upon a service office at the Washington, DC, VA regional office; and called for development of an on-the-job training program for full-time, paid service



officers. In April 1978, the board voted to establish five regional service directors to supervise and manage 30 service officers in 26 chapters.

By 1980 the program had moved out of the chapters and into local VA regional offices and VA medical centers around the country. Sixty-two NSOs worked in 45 offices and a full-time staff worked at the Board of Veterans' Appeals. Later, the program's name was changed to Veterans Benefits Department (VBD).

"PVA's service program came to be known for its professionalism and high-quality training," said Louis Irvin, acting deputy executive director. "Our NSOs excelled in ensuring that veterans with spinal cord injury and disease received all benefits to which they were entitled. Specialized training in ancillary benefits, such as accessible housing, special monthly compensation, automobile adaptive equipment, and vocational rehabilitation, to name a few, gave our NSOs the background they needed to advocate for the full range of benefits available."

In 1989, VBD was reorganized. The former Medical Affairs, Research, and Development Department (MARAD) was added and renamed the Medical Services Program. The service offices, national field directors, and national service director became the Field Services Program, and the appeals staff became the Appellate Services Program. After creation of the U.S. Court of Veterans Appeals, VBD established the Veterans Appeals and Litigation Office to give PVA members the opportunity to obtain free legal representation before the new court. VBD has since become responsible for working directly with VA at the national level on all three branches of VA: the Veterans Benefits Administration, Veterans Health Administration, and the National Cemetery Administration.

"PVA's reputation—and consequently that of its NSO program—is one of credibility," Irvin said. "Since the granting of our charter, the service officers have helped veterans file claims for benefits, monitored their health care and the progress of their claims, and advocated for them in their dealings with VA. VBD staff members play a key role in the mission of this organization, often with support and legal expertise from the Office of General Counsel. VBD also monitors overall trends in VA's administration of benefits and health care."

Field Services

The late Ernie Chavez left Albuquerque, NM, in 1943 to join the U.S. Army. An automobile accident in 1955 caused his spinal cord injury. Chavez joined the Paralyzed Veterans of America and participated in chapter activities. However, he became most associated with the development and progress of VBD. This was prior to the congressional charter, and he and other volunteers worked through another service organization to obtain benefits for PVA members. Chavez was among the first Paralyzed Veterans of America service officers accredited by VA.

Alan Langer became national service director in September 1971. His task was to organize the service program. Chavez became one of PVA's first salaried service officers, operating out of PVA's first national service office in Albuquerque, NM.

Having service officers available to help veterans was an important first step, but it was soon realized that the skills and quality of representatives was extremely important, as well. That meant training.

From the start, Chavez was involved with training. Service officers received two weeks of intense instruction, but much of their training still tended to be on the job, trial and error. The process of hiring people with experience, training those already in the program, and instructing new employees who had no prior experience in service work was difficult. When financial resources increased, the Paralyzed Veterans of America was able to begin organizing a salaried, truly professional program.

In 1974 the Paralyzed Veterans of America began to fund three-week periods of training, aimed at a roster of regional officers who would serve as accredited NSOs. The NSO Candidate Training Program was formalized in 1987 with the introduction of a comprehensive system of testing. Today, all NSO candidates must complete an intensive 16-month program. In addition to benefits, they study office operations, anatomy and physiology, medical terminology, and hospital procedures for problem resolution. They participate in postgraduate training to keep in step with the ever-changing benefits arena.

NSOs provide free representation to veterans with SCI/D and their dependents before VA, the Department of Defense, and other local agencies. The VBD staff oversees NSO training and locations, ensuring that each is fully competent in helping veterans file claims and pursuing appeals of those claims not properly granted by VA.



PVA's response to the needs of members in the Gulf Coast area after Hurricane Katrina in 2005 was swift. Above: DeWayne Grasty (left) and Rodger Clark present PVA disaster relief funds to James Parker, whose home was 80 to 90 percent destroyed.

"We always seek to improve the quality of representation we provide to our members and other veterans," Bo Rollins, acting associate executive director for Veterans Benefits, said. "We currently are focusing on reaching out to combat veterans of Afghanistan and Iraq to ensure they are well represented. We have a major focus on training our NSOs and management staff. We are also expanding the program and will provide offices and NSOs at the four new SCI centers VA intends to build. A long-term goal is having an

assigned full-time senior benefits advocate in each SCI center.”

The network of service officers located in VA medical centers and regional offices throughout the United States and Puerto Rico forms the foundation of services to paralyzed veterans. In addition to monitoring medical care, NSOs assist veterans in filing claims for benefits. They also develop and initiate appeals for benefits that VA denies. The Paralyzed Veterans of America has helped thousands of veterans obtain millions of dollars in current and retroactive benefits. In addition to those with SCI/D, they also represent servicemen and women with other severe disabilities, such as amputations, burns, head injury, diabetes, and cancer.

“Many accomplishments may be invisible to the eye, but behind the scenes PVA moves in leaps and bounds,” said Alan Munn, NSO II in Indianapolis. “NSOs spend an exorbitant amount of time on the phone or working claims and trying to fix problems regarding medical benefits, treatment, prosthetic or pharmaceutical needs, and, at times, personal family issues. We work simple claims as well as those that are so involved we never know when we will get to the end or whether we will be successful.”

“Our members rely on our nationwide staff of highly trained and skilled NSOs and support staff to advocate for the high-quality health care and hard-earned benefits they deserve,” Rollins said. “Without the fine representation of our NSOs, some members may go without these benefits.”



National service officers help veterans file claims and pursue appeals of denied benefits. Ramond Bruce (left), senior benefits advocate in Tampa, advises PVA member David Scott Williams.

Medical Services Programs

The Medical and Research Affairs Department was transferred to VBD in 1992. The Medical Services Program was developed to monitor VA's medical care and treatment of veterans with SCI/D. The only veterans service organization with a team monitoring quality of care for veterans with SCI/D, the Paralyzed Veterans of America relies heavily on its Medical Services professionals, who conduct site visits at VA facilities with spinal cord injury centers, SCI support clinics, or SCI primary care teams. Site visits improve the quality of care by creating consistency in practices and standards across the country, ensuring a continuum of care in the appropriate health-care facility.

The 1995 reorganization of VA's Veterans Health Administration (VHA) from four regions into 22 Veterans Integrated Service Networks made it more critical than ever to galvanize efforts. Acting in response to VHA's decentralization, serious new VA budget constraints, and the deep concern expressed by the Paralyzed Veterans of America Board of Directors about

variations in care within service networks, VBD escalated its efforts to monitor VA medical care nationwide. Staff increased visits to VA SCI centers, and VBD expanded training of personnel nationwide and added professional medical staff.

"Medical Services provides a direct connection to our members to ensure that their health-care needs are met," James Dudley, director of Medical Services, said. "Our staff monitors health care provided by VA via reports from our national service officers and annual visits to each VA SCI/D medical care center. Our toll-free health-care hotline provides a link between members and a medical professional to discuss special needs."

Because of PVA's close monitoring of the services provided to members and other veterans, this program also has an impact on the health care of all veterans who use the VA system. The Paralyzed Veterans of America works with VA to raise the quality and timeliness of care to the veteran population. Reports of the findings during an SCI site visit and recommendations for change are provided to VA as well as Congress.

Medical Services staff members consult with SCI/D professionals throughout the country and provide recommendations and solutions to improve health care for veterans. They act as advocates for veterans seeking benefits and health care from VA. Suggestions regarding VA staffing, equipment, and patient care have greatly improved the working environment of employees and quality of patient care. For example, one SCI/D center was considering closing a portion of its beds, a measure PVA opposed, and, through efforts of the local service officer, Medical Services, and the SCI chief, hospital administration decided the beds should remain open. In another instance, Medical Service staff also recommended the installation of ceiling lifts to ease patient transfers, an idea that has been adopted nationwide. Countless staff and patient injuries have been prevented as a result.

The site visit program has been expanded to include VA "spoke" facilities—those that provide initial care but don't have an SCI/D center. Medical Services is a review resource for VA medical care policies and directives.

"We are instrumental in recognizing 'best practices' across the VA system, and we provide the mechanism to share this information to all treatment centers, improving care for PVA members," Dudley said. "We will never falter in our commitment to improve the long-term care services to SCI/D veterans by working with VA. In addition, working closely with the Research, Education, and Practice Guidelines Program, we continue to assist our members with the latest medical information to improve their quality of life. Our department will continue to influence the care provided not only by VA but also the entire health-care community for Americans with SCI/D."

Appellate Services Program

When local VA facilities deny veterans' benefits claims, the Appellate Services Program provides legal representation at VA's Board of Veterans' Appeals (BVA) in Washington, DC. Appellate Services also prepares and presents cases before various military boards to ensure PVA members receive maximum benefits from the military.

Appellate Services "provides an opportunity for the comprehensive review of a claim and the presentation of evidence and legal analysis on behalf of our members, for benefits at the highest level within BVA—the administrative process of the U.S. Department of Veterans Affairs," said Fred Mullen, director of Appellate Services. "This results in benefits granted on appeal that would otherwise be denied in many cases." PVA has maintained one of the highest percentages of appeals granted and the fewest denied of any organization representing appeals at the BVA—all at no cost to its members.

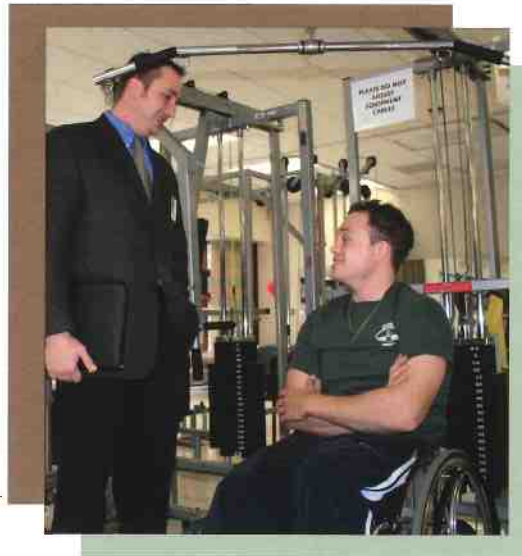
The Appeals Office (now Appellate Services) was established in 1979. In 1981 the program repre-

sented 135 appeals and cases, but as its successes and the need for its services grew, the number reached 19,704 by 2005.

Through Appellate Services, veterans can bring claims to the attention of the Compensation and Pension Service (C&P Service) of the Veterans Benefits Administration (VBA) via an administrative review in order to correct prior errors by VA that resulted from misapplication or misunderstanding of VA rules or policies at various offices around the country. This results in additional awards of benefits and correction in the decision-making process at these offices by the direction of the C&P Service. This improves the consistency of awards across the country.

In addition to representing clients before the BVA and VBA, members' cases are presented as needed before military boards and departments, with appellate action extending to all benefits administered by these government agencies. For instance, Appellate Services represented a sailor with SCI at a formal hearing before the Navy Central Physical Evaluation Board. The Navy had decided that the veteran had recovered to such an extent that he should be rated 20 percent disabled and separated with disability severance pay, a one-time payment with no ancillary benefits from the Navy.

The Paralyzed Veterans of America directed the questioning of the sailor during the personal hearing, presented medical documentation, and brought out the visible manifestations of functional impairment resulting from the sailor's attempt to perform daily activities, such as tying shoelaces.



In addition to benefits, NSOs are trained in anatomy and physiology, medical terminology, and hospital procedures so they can provide an array of services. Pictured: Robert Hager, NSO II in Denver, with James Crosby, Operation Iraqi Freedom veteran.


As a result, the Navy retired the sailor with a permanent 70 percent evaluation, with all of the privileges of a military retiree.

The work of Appellate Services has an impact on other veterans as well. "Efforts on administrative review by the C&P Service result in a change in behavior and the decisions at several VA regional offices, thereby improving the quality of VA decisions at those stations and benefiting all claimants who seek service there," Mullen said.

A Partner for Life

Through its three components, the Paralyzed Veterans of America's Veterans Benefits Department has always surpassed expectations and will continue to do so. Nothing less will suffice.

"Without the hard work of this dedicated team of professionals, some of our members and many other veterans would not receive the benefits of a grateful nation for their service and sacrifice," Rollins said. "Our members deserve and expect quality health care for their life-changing injuries. VBD's advocacy throughout the years has helped countless individuals on a case-by-case basis, as well as improving the quality of all veterans by professionalism, dedication, and a passion that is unsurpassed."

"The Paralyzed Veterans of America and the Veterans Benefits Department will continue to improve services to ensure that our members receive the highest quality health care, benefits, and representation possible," Irvin said. **"PVA is truly a partner for life."** 

DON HYSLOP

Don Hyslop joined the Navy when he was 20 years old. After his first six-month tour, he received additional training and became a Navy SEAL. In the fall of '67, while on a reconnaissance mission in the Mekong Delta, he was shot. "I didn't know how bad I was hurt but I knew nothing was moving in my body," he said.

It was a while before Hyslop realized how serious his wounds were. He knew he was paralyzed but thought he'd recover. "I had polio as a kid. I had a good recovery from that, so I figured I would be OK. I was back in the States within a couple of weeks, to Fort Sam Houston. A few weeks later I was sent to the VA in Long Beach. But that time, with 40 other guys in the spinal cord ward, I pretty much knew what I was facing."



While at Long Beach, Hyslop met a representative from PVA who came to the hospital to explain the benefits of membership. He also met Jim Smith, head of the California chapter. "This was the first I'd heard of PVA," he said.

Hyslop retired from the Navy while still in rehab, but today an SCI veteran might be released in as early as two months—before VA has conducted its medical review and determined the degree of disability. This is a problem, Hyslop noted. "It's tough living with a spinal cord injury on basic military pay, especially if there are dependents. PVA has been working to correct this."

After rehab, Hyslop returned home to New Mexico and then enrolled at the University of Houston. He was then accepted into the Coronado Arts program and has lived in San Diego since. He ran into Smith again in 1981. Smith was hoping VA would open

an SCI center in San Diego and needed to show that there were enough SCI veterans in the area to justify the expanded facility. Hyslop agreed to help him.

"He handed me a stack of membership forms, and that's how we started the Cal-Diego chapter," Hyslop said. "PVA's office in Washington sends us chapter grants for our services and programs; there are no dues to belong to PVA. Here at Cal-Diego, we have two vans to pick guys up for appointments to physical therapy or whatever. We have sports programs...."

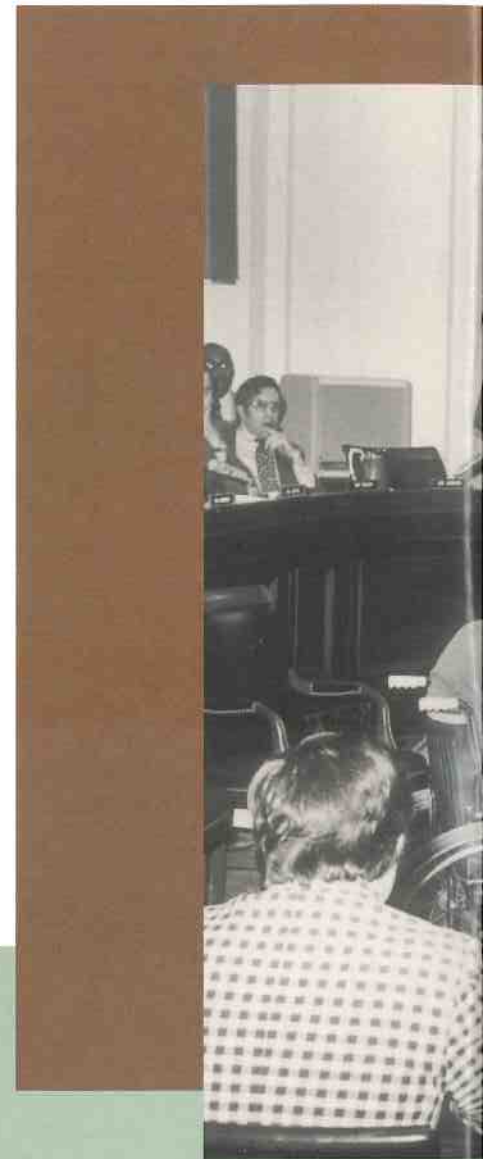
"PVA has been so important for vets in this country. The health-care benefits alone are tremendous—not having to worry about medical costs for wheelchairs, cushions, supplies, and so on. I wouldn't be where I am today without PVA."

Changing Policy & Law

PVA's founders, veterans just home from World War II, believed that the federal government should be responsible for the delivery of health care and benefits to our nation's veterans. They thought veterans had the strongest voice and could most effectively promote legislation for all similarly disabled. Ensuring participation in the legislative process began with this commitment.



Ensuring that Congress understands veterans' needs and fighting for changes to meet those needs has always been a PVA priority.



When delegates from the Paralyzed Veterans of America's first seven chapters met to organize on a national level, they passed a number of resolutions calling for improvement or expansion of veterans benefits, including specially adapted housing and automobile adaptive-equipment programs. They got involved in the fight for improved health care, calling on Congress to maintain appropriations for veterans' care. The leaders carried out these objectives by correspon-



ding with officials in the Veterans Administration and speaking out on Capitol Hill when necessary. Chapters conducted letter-writing campaigns.

“It appears that the approach to government relations for the first 20-plus years consisted of passing resolutions at conventions and the elected leadership pursuing these goals,” said Doug Vollmer, associate executive director, Government Relations.

But even with no formal government relations department, the Paralyzed Veterans of America was able to effect much change in its formative years. The young organization lobbied for a housing bill, which was introduced in Congress in 1947. Members testified in favor of the proposal, which would award a maximum grant of \$10,000 for adaptive housing, and the bill became law in 1948.

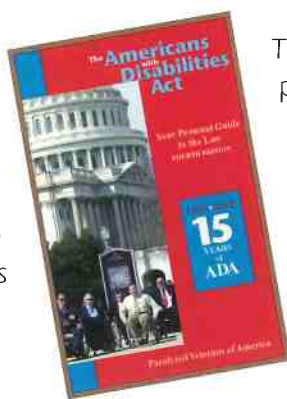
After the housing bill's enactment, the organization's leaders devoted more time and effort to the auto bill, which would extend grant assistance to quads and blinded veterans, and other legislative goals. President Truman twice vetoed the auto bill after Congress passed it, but the Paralyzed Veterans of America kept pressing, and in 1951, Congress overrode the president's veto. Another bill authorized direct VA home loans to veterans eligible for the special housing grant to finance the rest of their mortgages. The Paralyzed Veterans of America supported the bill's provisions in 1961 and promoted it through each Congress until its enactment in 1970.

Over the years, as the scope of benefits and programs of interest to members of the Paralyzed Veterans of America expanded, the need for greater involvement with all aspects of government led to today's Government Relations Department, and a more formal approach to legislative matters. "As PVA's resources grew, the organization was able to devote more to meet the needs of its members, and as they became more involved they recognized that as each layer was addressed, another appeared—similar to peeling an onion," Vollmer said.

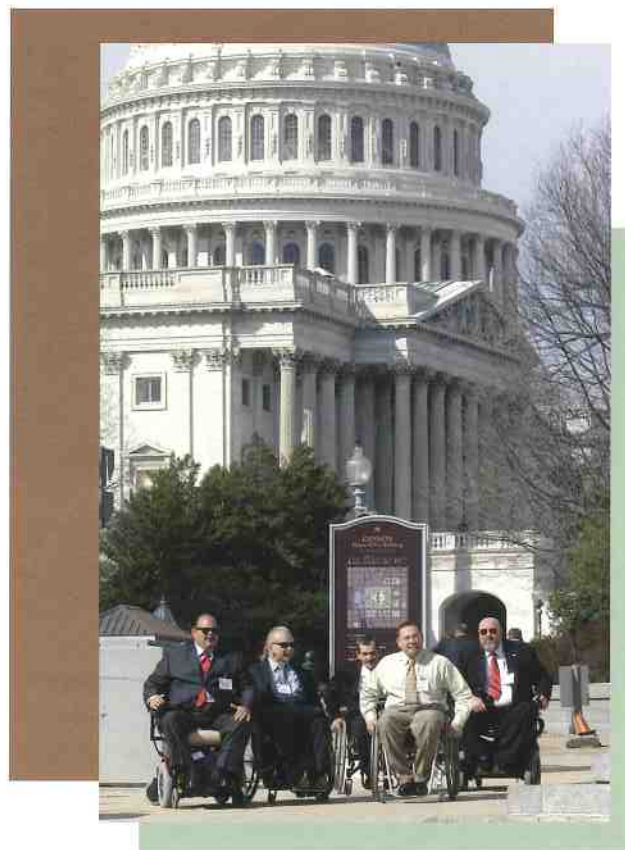
By the mid-1970s, a defined legislative program had been established. An advocacy program addressing broad disability issues was created in the late 1970s.

Advocacy: Maximizing Access, Minimizing Barriers

The National Advocacy Program handles a wide variety of issues, including accessible housing, transportation, Social Security, and health care. Advocacy staff follow relevant federal legislation from introduction through the legislative process and work with federal agencies to define the implementing regulations of new laws.



The Americans with Disabilities Act (ADA), passed in 1990, is one of the most significant legislative victories in which PVA has been involved. Passage of the ADA was the result of a concerted effort by Advocacy and the broad disability community, and Advocacy continues such efforts, working with federal agencies to develop strong regulations. The ADA applies to all people with physical or mental impairments that substantially limit one or more major life activities, such as walking, talking, hearing, seeing, learning, performing manual tasks, or caring for oneself. Under the ADA, people with disabilities cannot be denied employment or discriminated against in the employment process just because they are disabled. In addition, public accommodations, such as restaurants, libraries, parks, transportation, and sports arenas, must be accessible to people with disabilities. Services provided by state and local governments must meet accessibility requirements, as well.





Maintaining a strong presence on Capitol Hill, PVA members ensure that the needs of SCI veterans are not overlooked.

The late 1980s and early 1990s were exciting times for advocacy on behalf of people with disabilities. "The ADA was moving through Congress, and I believed it was the most important piece of civil rights legislation for people with disabilities in our country's history," said Fred Cowell, former PVA National Advocacy director and current associate director, Health Analysis. "In addition, the Air Carrier Access Act was on the front burner along with PVA's Access to the Skies Program. The Fair Housing Act Amendments had been passed in September 1988 and were moving through the regulatory phase, and demonstrations by people with disabilities for accessible public transportation were making headlines all across America. The challenges were great, but the possible rewards were greater."

"We tackled some of the greatest civil rights legislative challenges ever confronted by PVA staff. PVA chapters played a major role and sent thousands of letters and cards and made phone calls to their members of Congress. Working for passage of ADA was perhaps PVA's greatest grassroots advocacy effort," said National Advocacy Director Maureen McCloskey.

But years before the ADA, the Advocacy Program had helped secure passage of legislation that improved many aspects of the lives of those with disabilities. Even prior to the program's formal creation in the 1970s, the Paralyzed Veterans of America worked to achieve a barrier-free society and pushed for passage of the Architectural Barriers Act. Signed into law by



PVA members serve witness as President Reagan signs the Voting Accessibility for the Elderly and Handicapped Act in 1984.

President Lyndon Johnson in 1968, the act stated that all federal facilities built or remodeled from that point forward must be accessible to all citizens.

Delegates at PVA's annual convention in 1976 pledged a major commitment to eliminating architectural barriers and making mass transit accessible. When Washington, DC, decided to build its Metro system, its design was not friendly to wheelchair users. PVA tried to offer ways to make the system accessible. But Metro resisted. So PVA, along with other organizations, sued Metro, citing the Architectural Barriers Act of 1968. The judge ruled against PVA, saying federal financing



As a result of a lawsuit PVA brought against the Washington, DC, mass transit system, Metro is today barrier free.

did not apply to the act. But acknowledging PVA's "reasoned voice" and noting that time after time its recommendations proved out, the government put PVA in charge of making sure the Metro system was barrier free.

PVA Advocacy worked to apply civil rights legislation to air transportation, suing the federal government for failing to enforce antidiscrimination laws. For 10 years this case wound through the courts, and in 1986 the Supreme Court ruled that airlines were

not subject to existing federal antidiscrimination statutes. But within 88 days of this decision, thanks to PVA's work with the House and Senate, the Air Carriers Access Act, which states that all Americans must be treated equally when using commercial air carriers, became law.

PVA's Access to the Skies program brought together airline and airport officials, consumers, and regulators to find solutions to the problems air travel presents for people with disabilities. PVA also worked with the Department of Transportation and bus and rail operators to make fixed-route main-line transportation accessible.

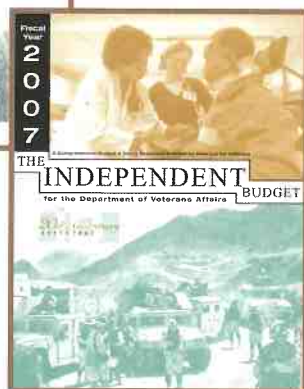
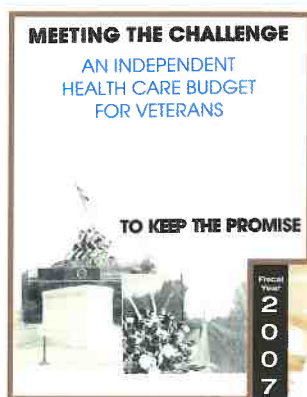
One of the most fundamental rights for Americans, the right to vote, was often denied people with disabilities because of inaccessible polling locations or voting machines. But in 1984, PVA helped secure passage of the Voting Accessibility for the Elderly and Handicapped Act, which mandates that federal registration and polling sites be wheelchair accessible and that voting and registration aids be available for people who are elderly or have disabilities.

Other significant legislation includes the Fair Housing Act Amendments of 1988, which made it illegal for landlords or developers to deny people with disabilities the chance to make reasonable modifications to properties or housing units. PVA was again instrumental in the victory.

Today's Advocacy team continues to be a strong voice for paralyzed veterans and the disability community. Lobbying on Capitol Hill, educating industry, ensuring compliance, and putting laws into action, PVA Advocacy helps turn policy and regulations into real access for people with disabilities.

Legislation: Preserving and Enhancing Benefits

The Legislation Program closely monitors actions by Congress and the administration. Whether testifying before congressional committees, meeting with legislators and their staffs, working with the Executive Branch, attending hearings, or following the progress of bills, the Legislation Program takes a stand on issues relevant to veterans and provides input to see those issues resolved in their best interests.



Throughout the years, the efforts of the Legislation Program have helped bring about important changes in programs and services for veterans and the disability community. For example, in 1976 the Paralyzed Veterans of America devoted considerable time and effort to the reform of the VA pension program for veterans with nonservice-connected disabilities.

"Other major legislative accomplishments have been achieved over the years, all directed at preserving and enhancing the benefits earned by PVA members and all veterans," Richard Fuller, National Legislation director, said. "Of particular note was PVA's work to upgrade the Veterans Administration to a cabinet-level department to ensure the needs and concerns of veterans were heard at the highest level of government."

After several years' effort, the Paralyzed Veterans of America won another hard-fought battle with the enactment of the Veterans Health Care Eligibility Reform Act of 1996. "This law contains two crucial provisions of great benefit to PVA members," Vollmer said. "The first ensures that the Department of Veterans Affairs cannot reduce its capacity to care for veterans with SCI. Second, the law provides for a higher level of access to care for veterans with a catastrophic disability, thereby protecting PVA members' ability to receive needed health care."

Perhaps the greatest challenge to veterans continues to be the need for adequate funding for the benefits and health care they receive from VA. The Legislation Program presents to Congress the

resource requirement for VA detailed in *The Independent Budget (IB)*, a budget and policy document that for the past 20 years has been produced by PVA and its partners in the veterans community. The Paralyzed Veterans of America is well aware that the VA health-care system and its SCI centers can operate

effectively only if Congress and the administration provide sufficient resources. The Paralyzed Veterans of America, through the *IB*, advocates for legislation to serve its members and other veterans with specialized needs, including ensuring such things as access and enrollment in the VA system, appropriate compensation, housing or automobile grants, medical and prosthetic research, insurance, long-term care, and veterans cemeteries. The significance of the *IB* was particularly evident in 2005, when it projected shortfalls of more than \$3.5 billion in the VA budget request, which VA was later forced to admit and to which Congress reacted quickly to correct.

Health Analysis: Working for All

The Health Analysis Program, originally called the Health Policy Department (HPD), created the Health Policy Department (HPD), created consumer publications, conducted VA SCI/D health-care utilization research, produced VA SCI/D Veterans Integrated Service Network (VISN) planning documents, laid the foundation for advocacy efforts concerning VA's Capital Assets Realignment for Enhanced Services (CARES) initiative, and founded the organization's efforts to produce clinical practice guidelines for the treatment of SCI.

"Today, VA is in the planning phase to construct four new SCI centers and add 100 SCI/D long-term-care beds because of the groundwork and advocacy of this prolific department," Cowell said.

The Health Analysis Program works to influence federal health policy affecting VA, Medicare, and

Funds for Health Care of Veterans \$1 Billion Short

2005 Deficit Angers Senate Republicans, Advocacy Groups

By THOMAS H. DODD
Washington Post Staff Writer

The Bush administration, already accused by veterans groups of cutting discretionary funds for health care next year, acknowledged yesterday that it is short \$1 billion for covering current needs at the Department of Veterans Affairs this year.

The disclosure of the shortfall angered Senate Republicans who have been voting down Democratic proposals to boost VA programs at significant political cost. Their votes have boosted the Paralyzed Veterans of America and other organizations down on the GOP.

"I was on the phone this morning with Secretary of Veterans Affairs Jim Nicholson, letting him know that I am not pleased that this has happened," said Sen. Larry E. Craig (R-Idaho), chairman of the Senate Veterans Affairs Committee. "I am certain that he is going to take serious steps to ensure that this type of outcome is not repeated."

The \$1 billion shortfall emerged during an administration and/or budget review and was acknowledged only during lengthy questioning of Jennifer H. Perin, VA undersecretary for health, by House Veterans Affairs Committee Chairman Steve Buyer (R-Ind.) at a hearing yesterday.

"We weren't on the mark from the start of the fiscal year," Perin testified. He said that the department has already had to use more than \$800 million from a fund that had been expected to be carried over to the fiscal 2006 budget, and that as much as \$200 million for planned capital spending will have to be shifted to pay for health care.

At a noon news conference yesterday, Sen. Percy Murray (D-Wash.), a member of the Senate Appropriations subcommittee covering veterans affairs and the lead sponsor of Senate Democratic ef-

orts to add \$1.9 billion to the VA budget, accused the Bush administration of underfunding "to make the sacrifices necessary to fund the program we have made to our veterans."

In a rare display of bipartisanship on the political lines of veterans spending, Craig appeared with Murray at the news conference and said he agreed with many of her comments.

Murray cited an April 5 letter written by Nicholson to the Senate in a bid to defend his amendment: "I can assure you that VA does not spend emergency supplemental funds in FY2005 to continue to provide timely, quality service that always our goal," he had said.

Murray added that they obtained a draft copy of the budget review in early April, suggesting that the department here of the budget problems at the time Nicholson wrote the letter.

VA spokesman Terry Johnston refused to release a copy of the document, saying, "We don't provide information about pre-decided budget problems and address reviews."

Nicholson issued a statement yesterday. "The health care needs of America's veterans are among VA's highest priorities. Working with our partners in Congress, I'm confident that VA's budget will continue to provide world-class health care to the nation's veterans."

Craig and other Senate and House Republicans declined to say how much the fiscal 2006 budget would be raised above the level proposed by the administration. They said any attempt to supplement the current fiscal 2005 appropriation will have to meet more detailed information on the shortfall this year. Craig said he plans to hold a hearing next week on VA funding needs.

Sen. Kay Bailey Hutchison (R-Tex.), chairman of the Senate Appropriations subcommittee on military construction and veterans af-

airs, said she had just been informed of the \$1 billion fiscal 2005 shortfall.

"We can never fall short on our promises to those who have sacrificed to us," Hutchison said.

The House has already approved a \$200-million Department of Veterans Affairs appropriation for fiscal 2005 that has been sharply criticized by the American Legion, the Paralyzed Veterans of America and the Disabled American Veterans.

Richard Fuller, legislative director of the Paralyzed Veterans, said the House problems this year and next were obvious to anyone visiting VA clinics and hospitals.

"The crowd is still happening, clinics shutting down, appointments delayed," Fuller said. Joseph A. Valente, legislative director of the Disabled American Veterans, said Perin's testimony yesterday confirms the veterans' assessment that the administration is "shortchanging veterans."

The Bush administration and House Republicans have been the main focus of anger among veterans organizations.

Their "policies are inconsistent with the interests of our members," said Steve Robertson, legislative director of the basic military value of an array of one, teamwork, taking care of each other," he said.

The administration and Congress, Robertson said, are promoting policies that "subverts veterans' health care, the ones who 'don't deserve' it and the ones who 'don't deserve' it."

Veterans groups are particularly angry with Buyer, who was specifically chosen by the House leadership to chair the House Veterans Affairs Committee. He kept operating details information on the shortfall this year. Craig said he plans to hold a hearing next week on VA funding needs.

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Sen. Larry E. Craig (R-Idaho), head of the Veterans Affairs Committee, says at a hearing "I was on the phone..." with Secretary of Veterans Affairs Jim Nicholson, letting him know that I am not pleased" about a \$1 billion shortfall in VA funds for health care. To his left are Democratic Sens. John E. Sununu (R-N.H.) and Jim Cooper (D-N.C.).

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group are bitter over the changes initiated by the Republican leadership in the jurisdiction of appropriate subcommittees. VA funding was shifted from the subcommittee that includes housing and NARA programs to the subcommittee on military quality of life and Veterans Affairs and related agencies, which forces the Veterans Affairs Department to compete for limited funds with such programs as Defense Department health care, military construction and military construction.

The American Legion is not about to write Congress and say "take away from DOD health care" [in order to boost VA funding]. "That's completely unacceptable," Robertson says.

The veterans group has already been back two controversial Bush administration proposals: a \$200-million for the veterans' health care system and an increase in the prescription co-payment, from \$7 to \$15.

Leaders of the American Legion, the Paralyzed Veterans and the Disabled American Veterans all noted a striking partisan division in Congress on veterans issues, with Democrats giving them much more support than Republicans.

Traditionally, Valente said, "the public has been supportive of defense," but he said Bush administration policies and votes in the House and Senate suggest that the GOP does not view the care of veterans as "a continuing cost of war."

In the 2004 election, exit polls showed that voters who had served in the military were decidedly more Republican than those who had not. President Bush carried the vote of five voters who had served by 16 percentage points, 57 to 41, with Sen. John E. Kerry (D-Mass.) barely won those who had not served, 50 to 49.

The Bush administration's priorities are "a little bit different now and veterans need a priority," Valente said. He described this as "terrible — I think it's unacceptable."

The Independent Budget accurately forecast VA budget shortfalls in 2005.

Medicaid in an effort to improve the quality and availability of specialized health-care services for PVA members and all people with disabilities. The program addresses long-term-care issues, including home and community-based options, personal assistance services, assisted living, and nursing-home care for veterans with SCI/D. Health Analysis is involved in the VA CARES initiative, which is designed to adapt VAs health-care system to the future needs of America's veterans. Continued access to quality VA health care for PVA members is a major focus.

"VA long-term care is especially important to PVA because we are an organization with an aging membership who can be expected to require more long-term-care services in the future," Cowell said. "Our advocacy is for expanded VA home- and community-based services that can keep our members home as long as possible but also for quality SCI/D-specific institutional long-term-care services when required."

Because the federal government can be expected to attempt to rein in the soaring cost of health-care programs over the next decade, it will become more and more important for the Paralyzed Veterans of America to analyze the implications of federal budget cuts to VA, Medicare, and Medicaid programs. *The Independent Budget* will become even more vital to its members' health-care interests as an increasing number of veterans turn to VA for their health care.


"Today, national health-care reform is still debated as the only answer to curbing the federal government's health-care expenses," Cowell said. "How VA would fare under such reform is questionable. PVA must remain vigilant to ensure the VA health-care system endures and continues to provide the quality services PVA members require."

No private health-care system can match the coordination and quality of VA's SCI/D health-care system, Cowell said. "These quality VA programs are the direct result of PVA's health-care advocacy, which must remain focused and engaged for the next decade."

The Veterans' Spokesman

The Paralyzed Veterans of America decided 60 years ago that it is critical to be an active and determined participant in the legislative and policy processes that shape the programs necessary for our members' well-being and full integration into society. Government Relations' mission is to ensure the availability of appropriate veterans' health care and benefits for PVA members.

"As an organization, PVA—particularly through the Government Relations Department—has become an acknowledged leading spokesman on behalf of the veterans' community in the area of health-care," Vollmer said. "This position has been bolstered by PVA's efforts in the areas of research, architecture, sports, and the lead in establishing and maintaining *The Independent Budget*. Similarly, PVA has come to maintain a high visibility as a spokesman on behalf of the benefits necessary for its membership to maximize their independence and enhance their quality of life."

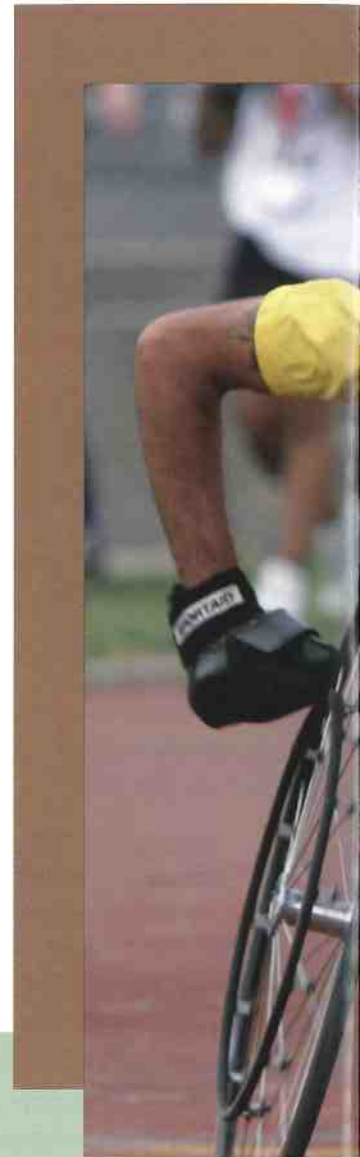
No other organization specifically addresses the needs of veterans with SCI/D. "PVA is an acknowledged leader in the area of transportation for individuals with mobility impairments, as well as being recognized as an active participant in the areas of access in general, housing, and voting rights," Vollmer said. "PVA has been successful because it has been willing to 'petition the government' to secure those benefits and services necessary for the membership's well-being. To reduce PVA's efforts in government relations would not only preclude future advances but also lead to the erosion of gains already made." 



Carl Blake (right), senior associate director, Legislation, testifies on Capitol Hill. Also pictured is Rep. Henry Brown (R-S.C.), House Committee on Veterans' Affairs Subcommittee on Health.

Health and Fitness for Life

The love of sports is one common denominator between those with disabilities and their able-bodied counterparts. The Paralyzed Veterans of America has since its beginning been a leader in the development of wheelchair sports in the United States.



For many people who have spinal cord injury or disease, the thrill of competition and unparalleled camaraderie that comes through participation in sports is one of the organization's most meaningful membership benefits. And there is something for everyone. Activities are numerous and wide-ranging, from such sports as table tennis, basketball, and swimming at the National Veterans Wheelchair Games (NVWG) to shooting sports and fishing.



Andy Krieger, director, Sports and Recreation, said the search for new and better athletic programs is continual. "The goal is to improve the quality of life of paralyzed veterans and expanding the quality and quantity of opportunities in sports and recreation. We look especially for those activities that enhance lifetime health and fitness," he said.

The Paralyzed Veterans of America can trace its roots to sports and recreation. The young men

who returned from World War II with paralysis were generally the same age and had similar problems and frustrations. Sports presented an outlet for some of their frustrations and energy.

Wheelchair sports began in earnest in 1946 in VA hospitals. That year California's wheelchair basketball team was limited to playing intra-squad games or games against able-bodied teams in wheelchairs. Bowling competition had

begun at several VA facilities. A national meet was set up in 1947, at the Paralyzed Veterans of America's urging, under the Victory Bowling Legion's sponsorship. The first game took place in the White House, with President Harry Truman casting the first ball. Before long, the wheelchair sports movement swept across the nation and crossed international borders.

In addition, paralyzed patients and their physicians recognized that sports could play an important, therapeutic role in rehabilitation. "Sports" included such sedentary activities as table tennis, catch, and billiards. Bowling, swimming, and volleyball were precursors to the more physically demanding water polo, softball, touch football, basketball, and rugby.

Wheelchair sports—more than any other single endeavor—proved once and for all to the world that severe disability was not a total handicap. And wheelchair sports more than anything else aroused great public and professional interest in the multifaceted problems of the spinal cord injured. Veterans' participation also showed the public that they were still active, able members of the community.

"In effect, our sports and recreation programs facilitated the establishment of PVA as well as wheelchair sports," Krieger said. "Today the program supports our mission by providing therapeutic programming for paralyzed veterans and other people with disabilities; this maximizes their independence."

At the convention in 1947, legislative issues and sports dominated the agenda. A sports focus continued in 1948 with concern about the standardization of rules for wheelchair sports. Harry



President Truman visits with PVA members.

Schweikert was the first national Sports coordinator (1947). All chapters were required to offer sports and recreation activities, which was good for recruiting new members. Schweikert's main duty was to report information to *The Paraplegia News* (now *PN*), thereby helping generate more interest among members.

"Basketball, track and field, table tennis, and bowling were offered way back then," said Cliff Crase, national Sports coordinator from 1970 to 1980. "It was a low-budget program at the time, with sponsorship dollars used for trophies. Chapters basically did their own thing."

"Whether we are involved in basketball or track or prefer fishing and hunting, the underlying reason for our activity is a desire to do those things we would do regardless of any physical handicap," said Richard Hoover, former PVA president, during the formal organization of the Sports Program. "The activity is emotionally and physically beneficial. It, as well, is a visible demonstration of the intent and ability of people with spinal cord injury to enjoy the same activities as everyone else in our society. For these reasons,

it is appropriate that we organizationally develop a comprehensive program that addresses all facets of competitive and recreational activity to better enable our members to participate.”

National Veterans Wheelchair Games

The National Veterans Wheelchair Games (Games), open to all U.S. military veterans who use wheelchairs as a result of spinal cord injury or disease, certain neurological conditions, orthopedic amputations, or other mobility impairments, encourages newly injured vets to become aware of their abilities and potential.

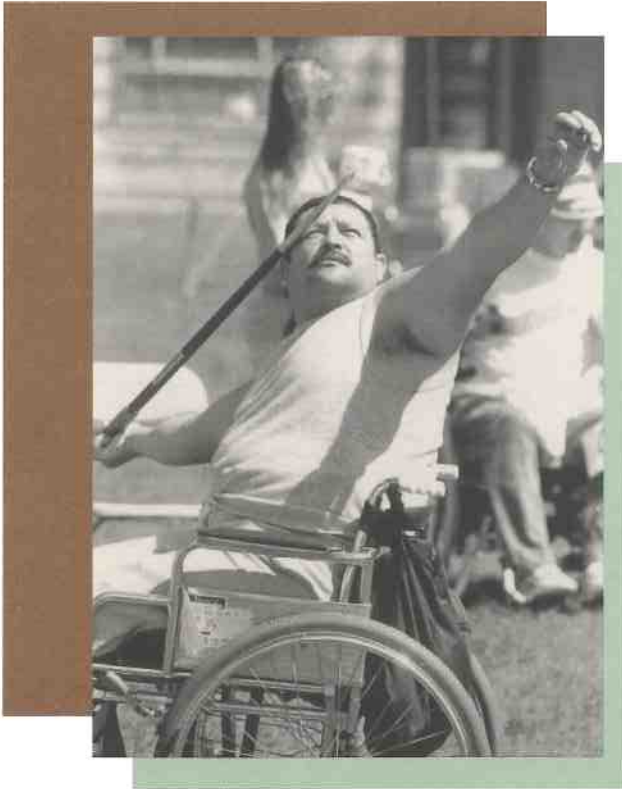


“As far as the organization’s sports and recreation programs are concerned, the National Veterans Wheelchair Games has no equal in terms of its annual participation, marketing revenue, and promotional capability,” Krieger said.

Although involved before 1985 in many aspects of the Games, since that year, the Paralyzed Veterans of America and Department of Veterans Affairs have annually copresented the event. Participants—experienced athletes as well as first-timers—have ranged in age from 18 to over 80. Recent years’ Games have averaged more than 500 athletes and coaches.



Because sports plays an important role in rehabilitation, PVA gets newly injured veterans involved in the National Veterans Wheelchair Games as soon as possible. Above: Kade Hinkhouse, Operation Iraqi Freedom veteran, competes in archery at the 26th Games in Achorage in July 2006.



The medal and exhibition events were designed for veterans with SCI/D, traumatic brain injury, and/or amputations. For many of the competitors, the Games are the starting point of a long-term relationship with PVA sports.

Keystone Chapter member Rory Cooper, PhD, explained how the Games have had an effect on his life: "Tim Davis, a Marine who had his legs amputated due to a landmine in Vietnam, introduced me to the Games in 1983. I won seven gold medals—and found my niche. I told my wife, Rosemarie, that it was the first time I had felt 'normal' in years. Being with so many positive veterans who used wheelchairs made me a lifelong fan of the Games."

Cooper began to compete in more track, road-racing, and swimming events. He went on to make the 1988 U.S. Paralympic Team, winning a bronze medal in Seoul, Korea. "During this period I became more involved with the PVA National Sports Program, sharing my engineering knowledge in new sports-equipment design

while competing at the elite level," Cooper said. "These were among my first opportunities to give back to PVA—the organization that had stood by me."

The National Veterans Wheelchair Games has always provided a new perspective on debilitating injuries for those newly injured: the realization that a sporting, competitive life is not beyond their reach. The Paralyzed Veterans of America is committed to ensuring that injured veterans from the current conflicts in Iraq and Afghanistan have every possibility to participate in the Games as soon as possible.

Generous sponsorship from corporate and individual donors enabled the Paralyzed Veterans of America to invite 29 vets from Operations Iraqi Freedom and Enduring Freedom (OIF/OEF) in 2006. PVA has made a commitment to continue to involve newly injured veterans in future Games.

"I have been struck by the poignant work we are doing to serve the recently injured troops," Krieger said. "During our initial efforts in 2004, four participants were OIF/OEF veterans. There were 22 the following year, and 26 in Alaska this year. These efforts have been expanded to include OIF/OEF participants in other non-Games events like the PVA National Trapshoot Circuit, the PVA Bass Tour, and hunts."

Fishing

Over the past decade, the Paralyzed Veterans of America's fishing program has increased in popularity and grown from one annual event to as many as six. In addition, it has become a bona fide "tour" sanctioned by the Bass Anglers Sportsman's Society (B.A.S.S.). The Bass Tour, which uses a competitive format to introduce fishing to people with disabilities, is one of the Paralyzed Veterans of America's most popular sporting events. Participants in tourna-



ments in various areas of the United States vie for Angler of the Year titles in “Open” and “Bank” divisions. For five years (2001–2005) the Grand National Championship (GNC) was the tour’s culmination, with winners earning coveted spots in the Citgo International B.A.S.S. Federation Championship.

Wheelchair user Jimmy Lankford advanced to the B.A.S.S. Federation Championship in 2003 and placed 14th out of 53 of the best able-bodied

anglers in the country. ESPN, The Outdoor Life Network, and Fox Sports covered the championship, highlighting his participation and accomplishment. Lankford found out later that the focus on him was not because of his disability but because he was doing so well in the tournament.

“It was a major statement for the disability community,” Lankford said. “I competed on the same level as able-bodied elite competitors and I held my own. It was an amazing feeling.”



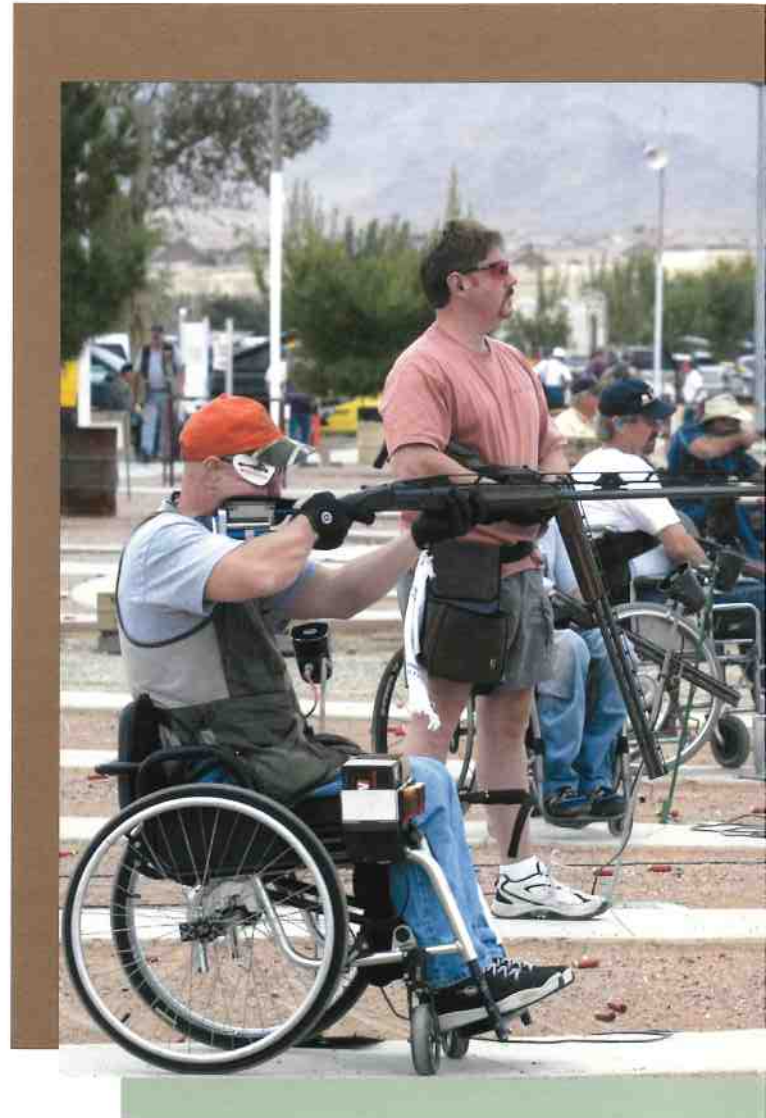
In 2005, 264 anglers with disabilities participated in the full range of Bass Tour events.

Shooting Sports

Trapshooting has been part of the Paralyzed Veterans of America activities since 1986, when the California chapter began sponsoring shoots. Other chapters followed, and the National Trapshoot Circuit is now in its 10th year. The circuit gives people with disabilities from all over the country an opportunity to learn and compete in this sport. One of the program's goals is to enable shooters with disabilities and those who are able-bodied to compete as equals.

"The Shooting Sports program has opened the doors to new opportunities all across the country, not only for PVA members but for everyone in the disability community," Krieger said. "Our hard work also has educated countless people everywhere—from landowners to outdoor guides to state and federal land managers—about the outdoor recreational needs of people with disabilities."

In addition to trapshoots, the Shooting Sports program coordinates other recreational and competitive activities, including big-game hunts. National Vice President Jack Franklin said, "I've hunted elk in New Mexico, ducks in Arkansas, deer in Georgia, and antelope in Wyoming. I have been in TV shows on The Outdoor Channel. The publicity these outings generate is invaluable. We can reach out to the general public and show what someone in a wheelchair is capable of doing, that we don't have to just sit back and watch."



Outdoors Advocate

A program of the National Shooting Sports Foundation (NSSF), Step Outside® encourages outdoor enthusiasts to introduce friends, family, and acquaintances to the fun and excitement of target shooting, archery, hunting, and fishing. The high-quality programs are therapeutic as well as recreational. For veterans with SCI/D, the activities sharpen hand-eye coordination and build confidence, outcomes that raise their quality of life.

In 2004 the Paralyzed Veterans of America and NSSF signed an agreement that enabled PVA to organize and host Step Outside® programs. It was hoped that this collaboration would attract



The PVA National Trapshoot Circuit is now in its 10th year, giving people with disabilities from all over the country an opportunity to learn and compete.

new participants to the Sports Program's shooting, fishing, and hunting activities. With Step Outside's® help, chapters could provide the established environment that newcomers need to feel welcome in the outdoor community.

"Our partnership with Step Outside® has allowed the resources for opening up new opportunities for PVA members all across the country," Krieger said. "This fantastic program has promoted the joys of trapshooting, fishing, archery, and numerous other activities."

The Disabled Sportsmen's Access Act of 1998 provided for outdoor recreation programs on

military installations to be accessible to disabled veterans, their dependents with disabilities, and all others with disabilities. It gave access to nearly 30 million acres of military lands for such sports as fishing, hunting, trapping, wildlife viewing, boating, and camping. PVA helped draft the legislation, which was cosponsored by Rep. Randy "Duke" Cunningham and Sen. Conrad Burns.

"As a former Marine, I have a special place in my heart for those men and women who have served our country and have become disabled as a result of their military service," Burns said. "When I was approached to work with PVA to improve access to outdoors programs, I was glad to help because I count hunting and fishing among my leisure activities."



Heritage Fund

"Sponsorships for the outdoor sports program supplement the national budget, therefore making more money available for other programs," Franklin said. "As this program grows, we will be able to provide more opportunities, not only for veterans but for the disability community as a whole."

In 2002 the Outdoor Recreation Heritage Fund (ORHF) was established to permanently endow the Paralyzed Veterans of America's many outdoor sports programs. The fund now has a Web page, www.pva.org/heritage/index.htm; a toll-free number, (877) 782-3648; and a registered Combined Federal Campaign Number, 0770. ORHF has enjoyed national exposure on The Outdoor Channel and in major outdoor-sports publications.




The National Veterans Wheelchair Games gives veterans with debilitating injuries the opportunity to see that a sporting, competitive life is not beyond their reach.

Moving Ahead

Krieger said he hopes to see programming added in areas that will allow people with disabilities who are confined to their homes or hospitals to remain actively engaged, but doesn't envision a great deal of change within the Sports and Recreation Program.

"PVA has already refocused its programming to stay attuned to its aging membership," he said. "For instance, Sports is less involved in physically competitive activities, such as basketball, quad rugby, and tennis, and more involved in outdoor recreational pursuits like fishing and trapshooting

than during its earlier years. These events, along with the National Veterans Wheelchair Games, are the ones our members enjoy most."

No matter what changes may come, the Paralyzed Veterans of America will continue to provide opportunities for sports and recreation, and these programs will remain one of the most valuable avenues for recruiting members and spreading the word about the organization. In seeing the participants as active members of society, the public learns their capabilities. They look at wheelchair users and say, "Look what they can do!" 

FRANK RIGO

I got out of the service in January of '46. In 1950, Harry Truman sent me a telegram saying, "Don't rush, but be at Hamilton Air Force Base in 48 hours because you're going to Korea." I was supposed to go that same day but missed my airplane because my physical took too long. My orders went to Korea but I stayed in California.

When they couldn't find me over there, I was missing in action and presumed dead.

Meanwhile I had kept on paying my military life insurance: \$4.50 a month. They would send back my payment with a letter: "Quit paying on the policy because you're dead." Eventually an American Legion service officer found my file and I was fully restored to life.



In 1958 I was in a car hit by a train. The car rolled three times and they found me lying on the ground with the car on top of me. They tried to drag me from under the car and called an ambulance. The driver needed to have breakfast before he could pick me up so they called another ambulance. They dragged me out, and then they dropped me off the stretcher. They couldn't kill me, though it seems they tried real hard.

I went to a Phoenix hospital. This was on a Sunday and the doc there was waiting for me to die so he could play golf. I wouldn't accommodate him. He didn't know how to get rid of me. They checked my wallet and found my World War II discharge in there. They said, "Hey, he's entitled to be dumped over at the VA hospital." They didn't expect me to live over there either but I fooled them all.

Eventually I was transferred to the Long Beach VA. While there, a guy named Ray Hinkle came to my bed and asked me, "You got three bucks?" I gave it to him and he said,

"You're a member of PVA." I didn't know exactly what that meant, but PVA did help me straighten out my VA and Social Security disability benefits.

When PVA started a chapter here in Phoenix, I became secretary, then a director. I attended the 25th anniversary convention in Los

Angeles and have not missed one since. In 1978 I was elected secretary. I stayed in that position for 25 years. I enjoyed doing it. I felt as if I was paying my dues for all the help I got from PVA.

The legacy of PVA is the benefits we fought for. There were no car grants for vets, no housing grants. All that came from us, fighting Congress for it. I think the greatest thing, which benefits the whole population in general, is all the curb cuts, ramps, and other accessibility changes we worked so hard to get. These changes benefit the people in wheelchairs but also the elderly who can't lift their feet, mothers with baby carriages.

I'll be 83 later this year. At the VA recently they put my information on a bracelet and the nurses said, "There must be a mistake, you're not that old."

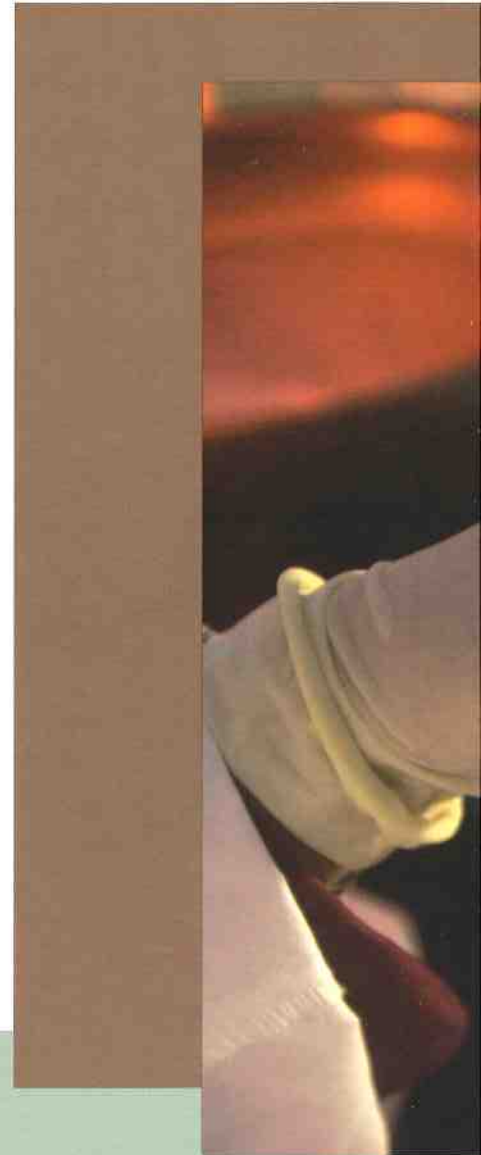
I still work—same job since 1963. Keeping busy, it keeps me going.

From Science to Service

One of the first actions of the Paralyzed Veterans of America at its founding meeting was to frame a resolution for formation of a Research Committee to promote research in medical fields connected with spinal cord injury. A commitment to research has been an integral part of the organization ever since.

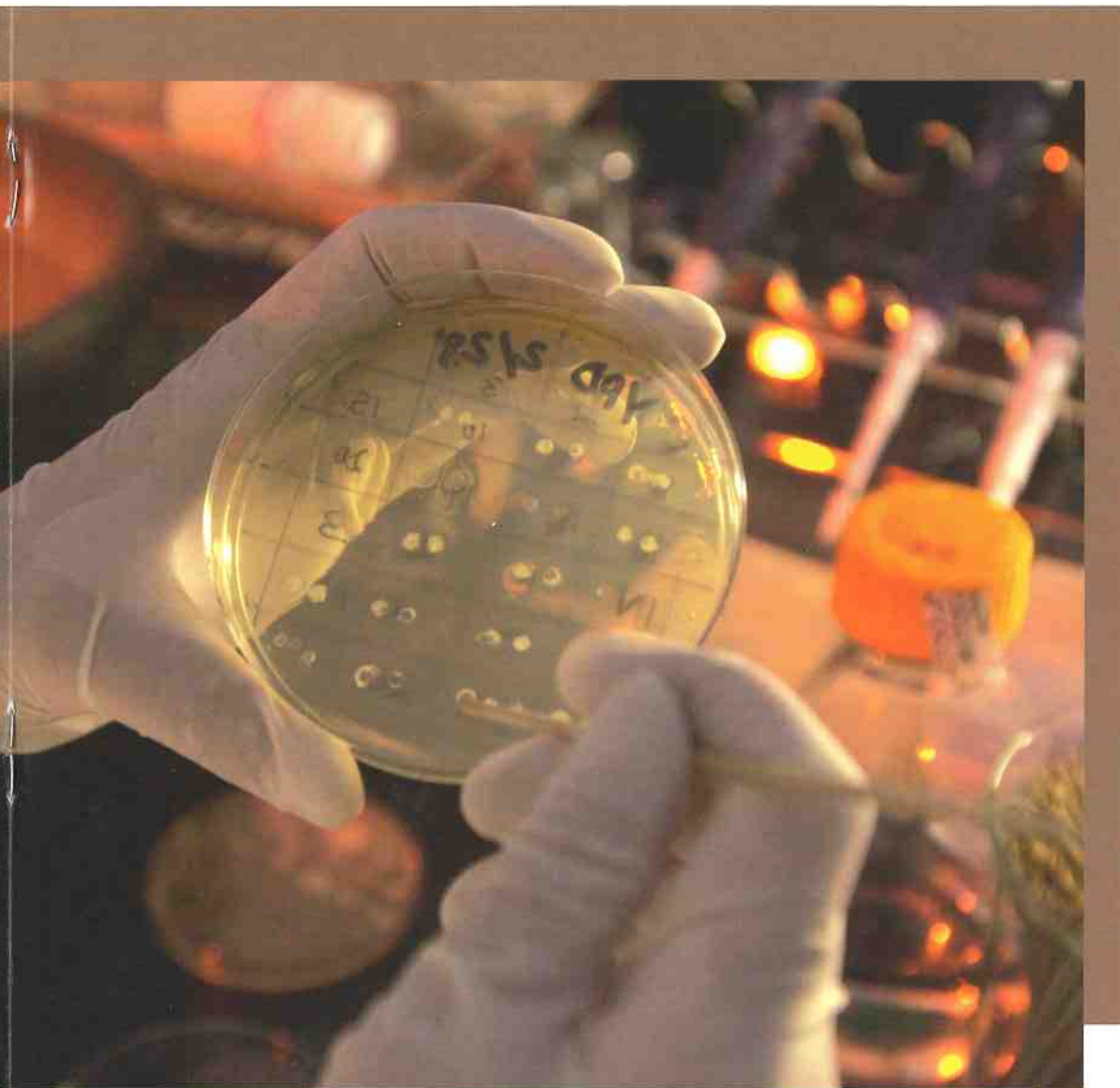


(left) Dr. Inder Perakash, a leading authority on SCI, holds the chair of spinal cord medicine at Stanford University.



Through its Research Foundation (1976), Education Foundation (1986), and the Consortium for Spinal Cord Medicine (1995), PVA has been a leader in sponsoring promising studies to address the consequences of paralysis and to search for a cure, while developing educational programs to ensure that people who are paralyzed have every opportunity to lead productive lives and participate fully in their communities. The Consortium completes a





science-to-service loop by developing clinical practice guidelines (CPGs) on selected medical topics based on scientific evidence.

"The research component is what makes PVA significantly different from other veterans service organizations," said Thomas Stripling, director, Research, Education, & Practice Guidelines. "Over the years, PVA has funneled considerable resources into projects that have immediate

impact, while never losing its commitment to tomorrow. Thanks to the program's long-term vision, a cure is no longer an impossible dream."

In the Beginning

In the early years of the organization, however, opinions were divided on where the emphasis should lie. Some members wanted to focus exclusively on providing services of immediate benefit,

while others wanted to include a research component that would look to the future. The compromise was to establish a research mission.

During the late 1940s and early 1950s, the organization tried to institutionalize support for research. With its small membership and modest budget, however, PVA was only able to support sporadic initiatives. PVA annually testified before Congress as to the importance of VA-sponsored research and supported early studies in functional electrical stimulation at the Bronx VA Medical Center, which were reported in *Life* magazine in the early 1960s. But research requires money, and the 1950s and 1960s were lean years for PVA.

At the 1971 PVA convention, delegates established a standing Research and Development Committee to screen, evaluate, and offer recommendations on all requests for research funds. In 1974 conventioners passed a resolution to create a technology and research foundation to screen and award funds for research programs.

One of the earliest grant recipients, Douglas K. Anderson, PhD, received support for two pivotal projects, which subsequently received significant VA, National Institutes of Health (NIH), and corporate funding. The first, in the 1970s, studied the processes that destroy tissue after injury and sought to identify potential therapies to prevent them. Building on this research, Anderson and other investigators completed animal and human trials. Their work resulted in the development of methylprednisolone, the steroid commonly used in the first eight hours after injury to preserve the greatest amount of function for patients at this critical stage.



(left to right) P. Hunter Peckham, PhD, a leader in the field of functional electrical stimulation (FES), with Michael Keim, MD, and their patient James Jatich.

Anderson's second study was on transplantation and cell replacement with embryonic cell tissue in cats. "Everything I have done with PVA has led me to a grant from VA and then to a clinical trial," he said.

Not until 1976 did PVA have the financial footing needed to establish its research program, the Technology and Research Foundation (TRF, which became the Spinal Cord Research Foundation in 1984). TRF, funded with \$250,000, advanced improvements in SCI care and the search for a cure. Initially, the concept was for the foundation to be a conduit through which PVA could funnel resources for research in SCI/D in a more systematic and scientifically valid process and free from politics. Thus the foundation was incorporated as a separate legal entity of PVA.

The foundation was, according to trustee Cliff Crase, "the leader in financing all research...regeneration, walking with electronic pulses, bladder surgery, wheelchair research, any prosthetics-type research... not only giving the money out but also following

up and coordinating medical doctors, scientists, engineers, and scientific-minded laymen. It was kind of a clearinghouse to get all these folks together.”

Progress

Prior to 1980, PVA had a program working with interested chapters to provide continuing education for SCI nurses in VA. To advance its education mission, in 1980, PVA embarked on a plan to create endowed academic chairs in SCI medicine throughout the country. With the help of the Bay Area & Western Chapter, the first such chair was established at the Stanford University School of Medicine with a pledge of \$1 million over a five-year period. The chair, permanently endowed by agreement in 1984, was intended to foster a research-oriented academic focus on SCI medicine, which would further the interest of doctors to be trained in this field and ultimately lead to its recognition and certification as a subspecialty by the American Medical Association.

Since its inception, the Stanford chair has been held by Dr. Inder Perakash, a leading authority on management of neurogenic bladder dysfunction, ways to stabilize the spine after injury, and strategies for starting rehabilitation as quickly as possible. Dr. Perakash was then and is still chief of the Spinal Cord Injury Center at the Palo Alto VA Medical Center, which is affiliated with Stanford University. Most recently Dr. Perakash's team has been studying the high incidence of diabetes in SCI individuals compared to individuals without a disability.

However, PVA soon realized that establishing endowed academic-based medicine chairs around the country was not

practical or cost-effective. Still committed to the goal of continuing education, in 1986 the board established the PVA Spinal Cord Injury Education and Training Foundation to give grants to provide educational opportunities for doctors, nurses, and consumers. It is known today as the PVA Education Foundation.

In the years that followed, PVA would contribute significantly to the field of SCI research. Some of the most outstanding researchers of that era got their start with PVA money. They include Peter Axelson, MS, ME, a pioneer in adapting rehabilitation technology for recreation; Stephen Waxman, MD, PhD, focusing on recovery of function in multiple sclerosis; Hunter Peckham, PhD, a leader in the field of functional electrical stimulation (FES); Rory Cooper, PhD, who designed the SmartWheel, a significant advance in wheelchair technology; Marc Tessier-Lavigne, PhD, working on cell regeneration; and Christine N. Sang, MD, MPH, studying the treatment of neuropathic pain.



Stephen Waxman, MD, PhD, director, Yale University PVA/EPVA Center for Neuroscience and Regeneration Research, has focused his research on the recovery of function in multiple sclerosis.

Regeneration research flourished during the 1990s. New drugs offered hope, and technological advances, such as lightweight wheelchairs and computer access, eased daily living. PVA's Research Program has often been at the forefront of groundbreaking research in SCI medicine, for example, funding of some of the first studies on the use of stem cells to treat SCI. Although now a very hot topic, at that time, stem cell therapy was off the SCI radar screen.

"The Paralyzed Veterans of America has supported innovative, state-of-the-art SCI research and education programs at hospitals and universities throughout the country," Dr. S. Laurance Johnston, former Research and Education director, said. "Reflecting our intergenerational contract between the past and the future, these programs, built upon previous PVA-supported research, laid the foundation for many of today's most promising therapeutic possibilities."

Medical Care Leader

Recognizing the benefits of promoting evidence-based standards for spinal cord medicine, PVA established the Consortium for Spinal Cord Medicine in 1995 to develop, produce, and disseminate clinical practice guidelines (CPGs) for the community of SCI health-care professionals and related guides for consumers. The guidelines provide the most current review of scientific evidence and recommendations on SCI care for health-care providers. Companion pieces tell consumers how to manage their own care. Guidelines are available on such issues as bladder

management, neurogenic bowel, depression, and other secondary conditions that can result from SCI. Several consumer guides have been translated into Spanish.

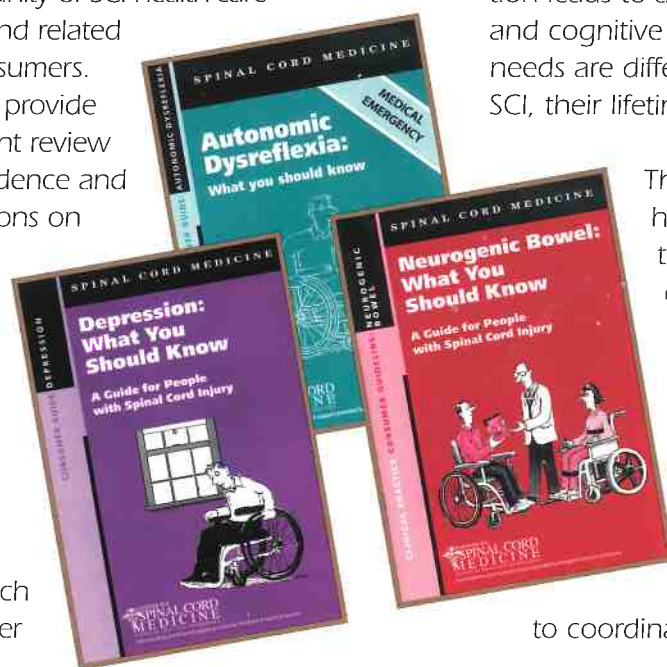
"One of the best aspects of the Consortium's work is the way it involves professionals from all the major health disciplines: doctors, nurses, occupational therapists, physical therapists, social workers, and psychologists," Stripling said. "These days, people with SCI are treated by a whole team of professionals. It's important for them all to be working off the same page."

Now published in electronic format, the guidelines can be accessed by hospital personnel at a moment's notice. Fred Frost, MD, at the Cleveland Clinic, considers this a valuable development. "On two occasions I was able to email the autonomic dysreflexia guidelines, within seconds, to a hospital service that was struggling to treat a patient with that condition. The electronic format may have been a lifesaver," he said.

Focus on MS

Approximately 20 percent of PVA members have multiple sclerosis (MS). Unlike the sudden, life-altering impact of a spinal cord injury, this condition leads to a gradual decline in neuromuscular and cognitive functions. Although their initial needs are different from those of people with SCI, their lifetime needs are comparable.

The Paralyzed Veterans of America has been committed to programs to treat MS issues, but its engagement deepened in 1998 when the Board of Directors passed a resolution calling for VA to vastly improve the organization of its care for MS veterans. As part of the work to fulfill that resolution, PVA became a leader in a partnership with congressional and VA staff to build a hub-and-spoke system to coordinate VA-wide services to veterans



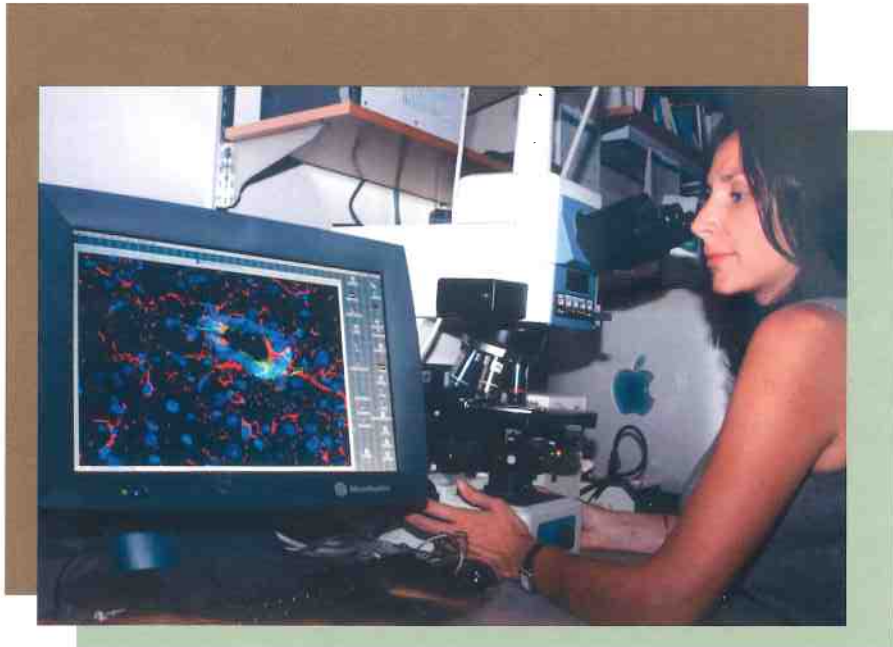
with MS. As a result of these efforts, Congress authorized in 2002 that VA establish two "Centers of Excellence." PVA also is involved with the Consortium of MS Centers (CMSC), a collaboration of North America's foremost veteran and civilian MS facilities.

PVA emphasizes programs that address the informational needs of people with MS as well. In the late 1980s and early 1990s, working with the National Multiple Sclerosis Society, PVA staff coordinated development of an MS self-care guide and cosponsored a widely broadcast annual MS educational teleconference. PVA also provided administrative and financial support to the Multiple Sclerosis Council for Clinical Practice Guidelines to develop a series of guidelines on MS issues, such as fatigue, urinary dysfunction, spasticity, and disease-modifying therapies. Unfortunately, the council disbanded in 2002 when PVA was unable to continue funding.

Varied Ventures

During the 1990s, PVA committed considerable resources to studying the economic consequences of SCI/D and MS, publishing three books—*The Economic Consequences of Traumatic Spinal Injury*; *Spinal Cord Injury: An Analysis of Medical and Social Costs*; and *The Economic Consequences of MS Among PVA Members*—that remain leading sources today. "Just as a thorough understanding of a problem is necessary before steps can be taken to address it, program initiatives must be built on hard data, not just ideas," Stripling said. "PVA was a driving force in instigating these studies, which have had major public policy implications."

A founding member of the International Campaign for Cures of Spinal Cord Injury Paralysis, PVA has



Dr. Sandrine Thuret, PVA Research Foundation grantee, conducts research in adult spinal cord regeneration.

committed funds to help develop an international data set to make the collection of SCI data uniform throughout the world. In 2004, PVA rekindled its involvement with RESNA, an organization that focuses on developing assistive technology for people with disabilities. Interactions with VA, the Department of Health and Human Services, Department of Education, NIH, Centers for Disease Control and Prevention, Institute of Medicine, National Institute on Disability Rehabilitation Research, National Science Foundation, and National Institute of Neurological Disorders and Stroke have broadened PVA's impact on public policy and expanded the programs and resources devoted to the needs of people with SCI/D.

Caring About Today

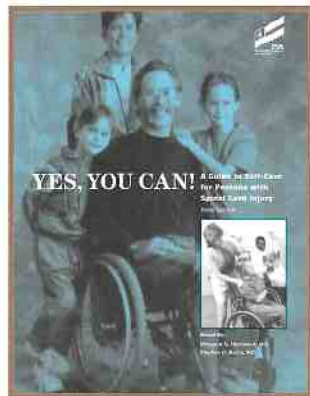
Research findings that sit on a library shelf without getting to the people who need them have little value. The Paralyzed Veterans Education Foundation is committed to expanding access to the growing body of knowledge about SCI/D.

Products funded by the Education Foundation are practical teaching tools built on what has been learned from research and through the develop-

ment of clinical practice guidelines. They are applicable to real life and can make a critical difference in quality of life following traumatic injury or diagnosis with a spinal cord disease.

Through the years, the Education Foundation has supported the development of books, videos, audiotapes, and CDs that teach consumers, caregivers, and health-care professionals how to build skills for managing SCI/D. One helpful and popular resource is *Yes, You Can!*, a self-care guide for newly injured patients. A well-received foundation-funded video is "EatRight® SCI/D: A Self-Directed Weight Management Program," developed by Dr. Yuying Chen, of the University of Alabama at Birmingham. Other projects have included work on pregnancy for women with SCI/D, booklets and videos on care for secondary conditions, and a CD on training personal care assistants.

"The demand for *Yes, You Can!*, initially published in 1989 and now in its third edition, is huge. It's certainly a 'best-seller' in the SCI community," Stripling said. "Earlier this year, our supply ran out, and by the time we were able to reprint it, we already had orders for 1,400. Many rehab professionals tell us they give it to all their patients, particularly those who are newly injured."



Focus on the Future

In 1987, the Paralyzed Veterans of America helped establish the Center for Neuroscience and Regeneration Research, a preeminent Yale University research facility located at the West Haven VA Medical Center. The center, a collaborative hub of a large international network of scientists, is regarded as one of the premier sites for training in spinal cord research. Directed by Stephen G.

Waxman, MD, PhD, the center has been studying what causes function to return after spinal cord injury or disease and during remissions in MS.

"PVA's financial support of our work is vital," Dr. Waxman said. "There is nothing like a person in a wheelchair sitting next to a scientist and asking questions. PVA is a silent partner saying, 'Keep going; keep going.' "

Today, the Research Foundation funds basic science, clinical applications, and technology research to discover better treatments and cures for spinal cord injury and disease. Its trustees are all paralyzed veterans, who base their decisions on priorities developed from a combination of personal experience and recommendations of the Scientific Advisory Board. This distinguishes the foundation from many other health research-funding groups.

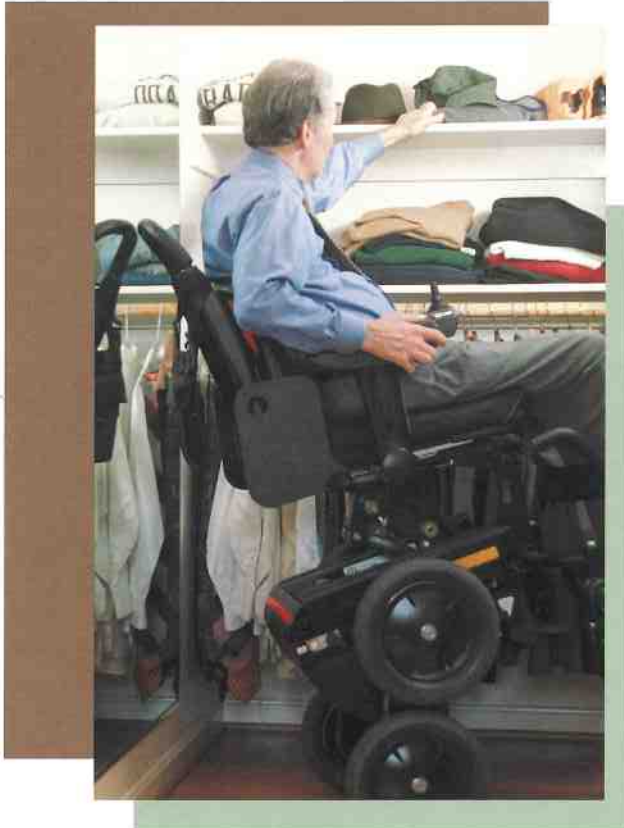
Since its inception, the Research Foundation has awarded more than \$41.5 million in research grants. Recently funded projects include studies of genetic approaches to nerve cell regeneration, therapies to restore function, new medications to control neuropathic pain following SCI/D, and stress and coping of SCI caregivers.

The Education Foundation has funded more than \$5 million in projects since its establishment in 1986. Recent Education Foundation projects range from a Web-based multimedia module on urinary tract dysfunction to an assistive-technology expo for Native Americans.

In 2005 the Research Foundation and the Education Foundation awarded grants for a combined total of more than \$1.5 million for spinal cord research and education.

Funding Fellowships

Fellowships are a powerful means of attracting new talent to the field of spinal cord research and medicine. The organization's strong fellowship program encourages young scientists to



Improved wheelchair technology contributes significantly to PVA members' quality of life.

explore SCI/D as a career path and help increase the ranks of clinicians certified in SCI medicine.

"A 2002 Johns Hopkins University Business School study found that 60 percent of our research grantees went on to obtain government funding, which generally requires that a project have at least some preliminary positive results," Stripling said. "By supplying smaller, start-up grants, we help young scientists break new ground and give wings to their fresh ideas."

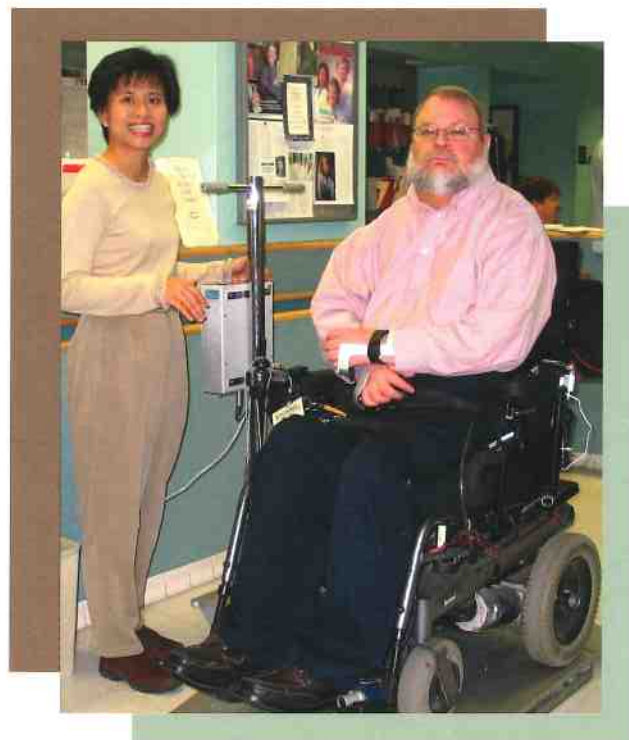
A sizeable bequest from member Fritz Krauth, who died in 2002, enabled the Research Foundation to establish the Fritz Krauth Memorial Fellowship, which is awarded to the highest-ranking fellowship applicant each year. In 2004, Dr. Xiaolin He, an AIDS researcher, received the inaugural Fritz Krauth Memorial Fellowship, which led him to bring his expertise in structural biology to the field of SCI research. Subsequent winners are

Dr. Mi-Ryoung Song (2005), for her work on the use of adult spinal cord cells for repair of a damaged cord, and Dr. Tanuja Merianda (2006), who is studying axonal regeneration.

"The Fritz Krauth Memorial Fellowship from PVA was the first external money I received, and I got it at the most critical point in my career," Dr. He said. "I could not have changed the focus of my research without first obtaining my own source of support."

Improving Wheelchair Technology

Improved technology can contribute significantly to quality of life by increasing mobility, independence, productivity, and the ability to function in the workplace and community. In 1995, PVA helped establish the Human Engineering Research Laboratory (HERL), a joint venture of VA, the University of Pittsburgh, and the University of Pittsburgh Medical Center. Under the direction of PVA member Dr. Rory Cooper, the HERL staff investigates adaptive technology for mobility



Dr. Yuying Chen (left) developed a self-directed weight management program for people with SCI.



Phil Klebine, 2005 PVA Education Foundation grantee, leads a class on secondary complications of spinal cord injury.

and manipulation (e.g., wheelchairs and hand controls), studies neuromotor control system function, and performs biomechanics and ergonomics research.

Recently, as wounded soldiers have returned from Operations Enduring Freedom and Iraqi Freedom, HERL has become involved in consulting with the Department of Physical Medicine and Rehabilitation at Walter Reed Army Medical Center.


"This collaboration encompasses joint research and education projects, including a series of workshops on translating research into clinical practice," Dr. Cooper explained. "PVA has supported these workshops financially and programmatically. Whatever the project, PVA has been there to support our work."

PVA has also helped develop and publish wheelchair performance standards. According to Stripling, such standards are "both science and service oriented—science because of the engineering and testing that goes into them; service because the

resulting information sets standards for manufacturers to meet and helps consumers to make informed decisions about wheelchair selection." Known as the ANSI/RESNA wheelchair standards, they also play a part in guiding equipment-reimbursement decisions by federal agencies.

Pushing the Boundaries

"Overall, today's SCI health care, taken for granted by many, sprang from PVA's long-term vision of what was possible when there was a commitment to the future," Dr. Johnston said. "Although I have worked for some of the nation's prominent public health agencies, none have had more heart and soul than PVA."

Through the PVA Research, Education, & Practice Guidelines Program, PVA is pushing the boundaries of research, developing innovative educational approaches, and broadening the dissemination of teaching tools. Our mission? To learn more, teach more, and help more people with SCI/D while pushing research forward until there is a cure. 

JOE ROMAGNANO

Joe Romagnano, a former police lieutenant in Mobile, AL, was diagnosed in 1971 with transverse myelitis (TM), a neurologic syndrome caused by inflammation of the spinal cord. Inflammation within the spinal cord interrupts the pathways that carry motor nerve and sensory fibers to the limbs and trunk and from the body back to the brain. TM causes limb weakness, sensory disturbance, bowel and bladder dysfunction, and pain.

When Romagnano became paralyzed, the local paper ran a story, mentioning that he was a veteran. The local chapter president saw the story and arranged to have a national vice president come meet Romagnano and tell him about PVA.



"Jim Smith came down and signed me up right there when I was in the rehab," Romagnano recalled. "I finished rehab in the civilian hospital but PVA was very instrumental in getting me into the VA medical care system, which at that time I didn't even know existed. Because I wasn't service connected, I didn't think I was entitled to use the VA facility. PVA took care of the paperwork; they had the knowledge and the expertise. They've been a tremendous asset to me over the years. A godsend, truly, a place to turn to."

Romagnano became an active member and started attending PVA conventions. "I was very interested in advocacy work at that time: ramps and accessibility and things like that," he said.

He was elected national vice president and two years later became president. "That's when I started the advocacy division. We worked hard, laying the groundwork for the

Americans with Disabilities Act. Back in those days the biggest issue was that a wheelchair guy didn't leave his house because he couldn't go anywhere. There were no curb cuts. You couldn't get on a plane without being carried, and they'd drop you. It was just a totally different world.

"Now, we have a lot more accessibility and PVA deserves credit; we worked the hardest to bring this about."

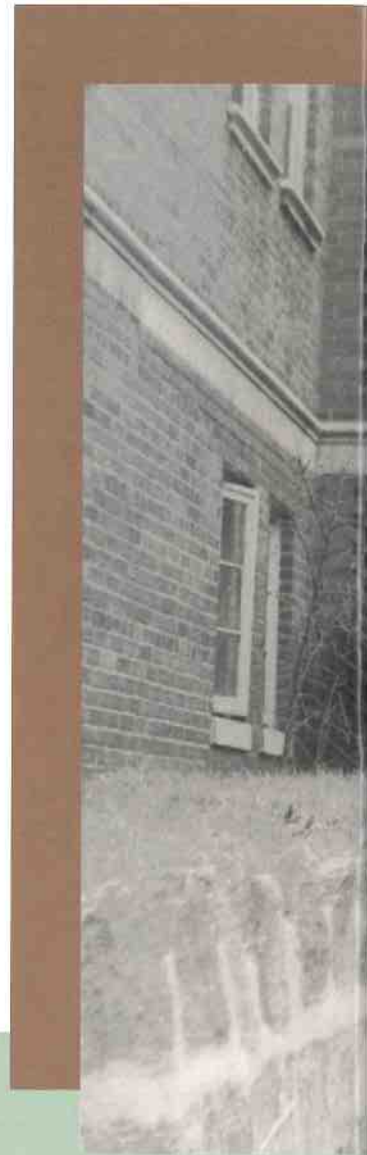
Romagnano, now 77, is still involved at the local level, with Bayou Chapter. He was president in 2005 when Hurricane Katrina hit, totally destroying chapter offices and many members' homes.

"The water came up 45- to 50-feet deep. We had members sleeping in cars, under tents. With swift action from the national office, we were able to offer our members immediate aid in the form of \$2,500 cash grants. We helped them locate accessible trailers; we made sure their needs were met. National sent down some satellite phones and a service officer to make sure our members' claims were handled properly.

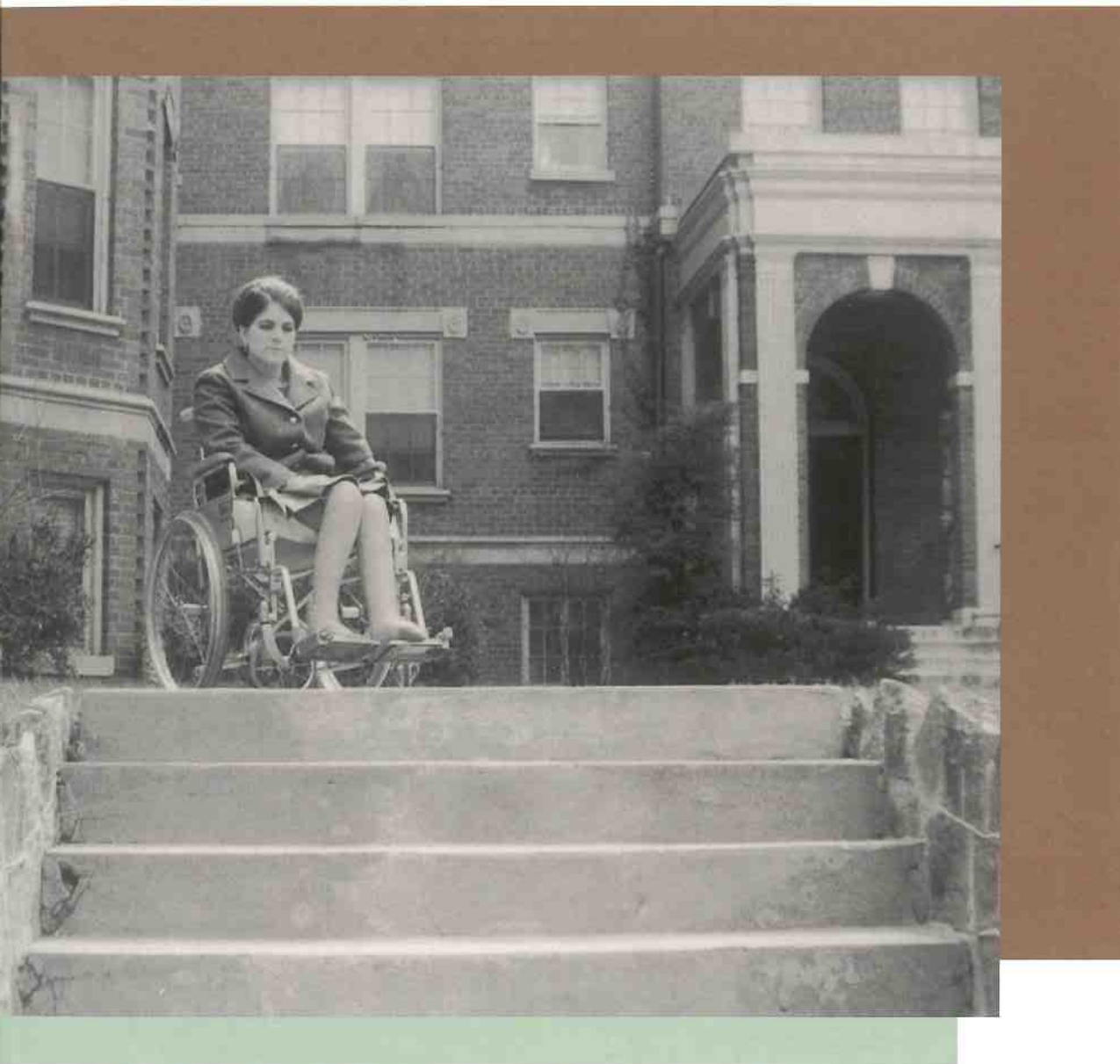
"Our main concern was our members, and we've got 'em all going pretty good now."

Barrier Free

In the 1940s most homes and public facilities—stores, schools, libraries, factories, restaurants, theaters, parks—presented barriers for the wheelchair user. Even the hospitals caring for the spinal cord injured veterans of World War II had not been designed to accommodate wheelchairs. After hospitalization, these veterans faced even greater challenges: Where could they live? Where could they work, shop, receive medical care...?



In a September 27, 1946, letter to the *New York Times*, the Paralyzed Veterans Association of Bronx County listed the new organization's social and economic aims. President Walter Suchanoff wrote, "We intend to publicize our needs for the specific types of housing which are required by the nature of our injury; also the necessity of obtaining materials and labor for making alteration in existing homes...."



In 1946 the New York Chapter of the American Institute of Architects (AIA) received a request from the Halloran (NY) association of paralyzed veterans for help in designing housing for paralyzed veterans. Six volunteer architects completed preliminary blueprints calling for a special bathroom, bedroom, office, and exercise room. The blueprints provided construction details for doorways, corridors, windows, closets, and garages. Requests for these

new accessible home plans came from all over the country.

During the February 1947 formative meeting, delegates from paralyzed veterans associations from around the country drafted resolutions outlining their basic concerns, including one for new federal grants for accessible homes. The resolution stated, "The member organizations of this associa-

Paralyzed Veterans Need Specially Built

Congress and State Legislatures to Be Asked To Provide Homes

By DICK ARMSTRONG

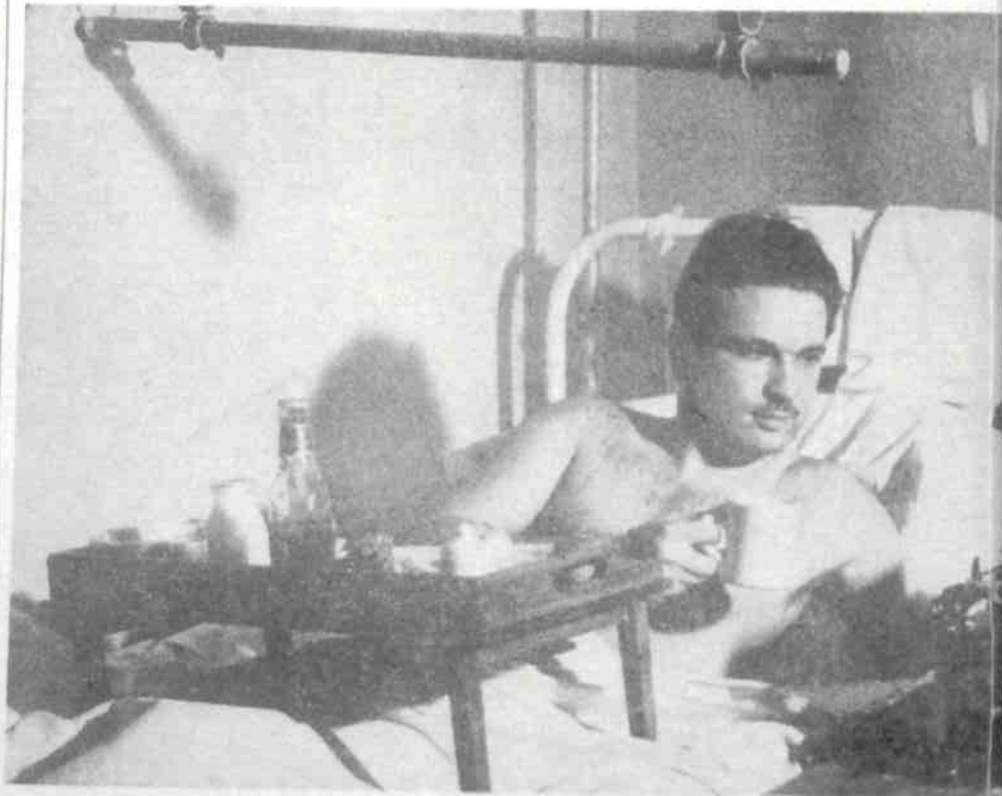
Fighting men whose war injuries have left them crippled for life are sweating out the peace in hospitals today because nobody has done anything about providing the specially adapted houses they require.

There are perhaps 2000 paralyzed veterans in the country. Ninety of them are in two New York City service hospitals—60 ex-soldiers in Halloran, 30 ex-gobs in St. Albans. They can't walk, most of them, but can still fight.

And this time they are fighting to collect the small debt of gratitude their country owes them. They don't intend to take the public's indifference lying down—or sitting in wheel chairs.

The 90 men in the two New York City hospitals, along with 65 already discharged but living in quarters unsuited to their needs, have organized the Halloran Chapter of the Paralyzed Veterans Association, and are taking definite steps to bring into existence the housing which will make possible their return to civilian life.

In their efforts, they have won the support of the CIO, and the whole-hearted cooperation of the New York Chapter, American Institute of Architects. They have



Robert Moss, executive director of the Paralyzed Veterans Association, is leading the fight for better housing. Moss, who hails from Long Island, was wounded in Italy and considers himself lucky that he can move about on his feet, though hesitatingly.

talk with the disillusioned and understandably embittered veterans. But we are determined and, for the veterans committee of the Union. David Finn, chairman of the veterans committee of the

tion shall form Housing Committees to investigate local problems...."

A federal housing bill was introduced in Congress later that year. The arduous two-year lobbying campaign had been headed by Robert Moss. He argued that paralyzed veterans were forced to remain in hospitals because their former homes could not accommodate wheelchairs. Paraplegic (accessible) housing was the remedy. His idea was realized on June 12, 1948, when the U.S.

Senate passed Public Law 702 (P.L. 702), under which the Veterans Administration later approved \$47 million for the construction of wheelchair-accessible homes.

Nine years later, at the 1957 convention, delegates approved a broad resolution that PVA should support the elimination of steps and stairs in public buildings. Furthermore, the organization's president, national officers, and local chapters should avail themselves of every

Houses



at to get proper housing for parap...
r than most of his buddies. He at
Photos by Irving Haherman
Chairman of attention of the politicians
the local will be forthcoming. They

(left) This 1946 *New York Times* article helped publicize the returning WWII paralyzed veterans need for specific types of housing that were required by the nature of their injuries. (right) A simple set of stairs to most—but an impossible obstacle for many decades.

A National Program Begins

For years, PVA's Architecture Program was run by an architectural barriers coordinator, but this position did not operate out of the national office. Finally, in 1975 the national office was authorized to create the position of architectural barriers director.

In 1986, the Paralyzed Veterans of America's Barrier-Free Design Program, which advocated for a barrier-free built environment, was expanded to include oversight of VA construction. This would become the Architecture Program. The development of PVA/VA liaison procedures was an important step in ensuring functional health facilities for paralyzed veterans.

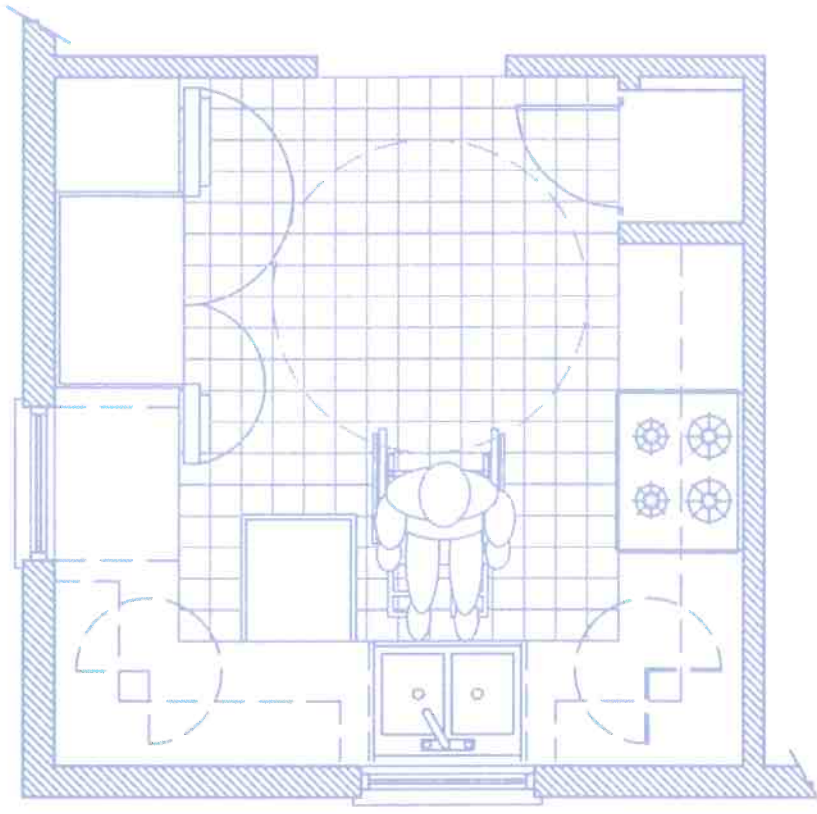


opportunity to promote this project with their civic leaders.

Over the next two decades the Paralyzed Veterans of America chipped away at the problem of inaccessible private and public places. Delegates to the 1976 convention then tackled inaccessible mass transportation. Thanks to the organization's expanded resources, they pledged a substantial sum (\$100,000) to eliminate architectural barriers in public-transit facilities.

This formal agreement set out specific points for the Paralyzed Veterans of America's involvement, at national and chapter levels, in the planning, design, and construction of SCI centers.

At its inception, the design program was unique in several ways. Most important, the Paralyzed Veterans of America became the only national disability organization with a staff of licensed architects. The timing was important. The VA SCI construction program was at its peak. In the late 1980s more than a dozen SCI centers were in the plan-



Coordinating Council on Spinal Cord Injury, AIA, National Association of Homebuilders, National Apartment Association, and National Multi-Housing Council. PVA President Victor McCoy and Architecture Director Kim Beasley met with the White House to discuss the coalition's recommendations, which were largely incorporated into the final Fair Housing design guidelines issued by the U.S. Department of Housing and Urban Development in March 1991. Paralyzed Veterans of America architects then wrote the *Fair Housing Design Guide* to help architects and builders understand the design requirements.

ning, design, or construction stage. Congress was considering critical new legislation, including the Elderly and Handicapped Voting Rights Act, the Air Carrier Access Act, and the Fair Housing Amendments Act—all of which had extensive architectural components. In addition, public awareness of the problem of inaccessible architectural design was increasing rapidly and, through its Architecture Program, the Paralyzed Veterans of America was able to maintain its national leadership role.

Because of the efforts of national disability organizations, including the Paralyzed Veterans of America, Congress passed the Fair Housing Amendments Act. This law made it illegal to prevent a person with a disability from making reasonable modifications to a housing unit and also required the construction of accessible private multifamily housing.

The Paralyzed Veterans of America was committed to ensuring the law's passage, assembling a coalition of organizations, including the National



Accessible home design is one priority of PVA Architecture.



PVA has led the way in setting standards for accessible seating with unobstructed sightlines at sporting venues.

Beyond Transportation

As accessible transportation improved, the demand for accessible hotels and motels increased. *PN* editor John Price noted in 1957, "The world is beginning to recognize the wheelchair traveling public." *PN* reported, "The recently opened Copper Hill Motor Hotel is the first motel built in the country with accommodations for paraplegics incorporated in its building plans. M.C. Montgomery, a California member, was the technical advisor on the construction of the wheelchair units." The new Arizona facility had opened on February 10.

In 1986, the Paralyzed Veterans of America entered into an agreement with the American Hotel & Motel Association to create a design guide for accessible lodging. In cooperation with the association, Architecture wrote and illustrated

Design for Hospitality, a comprehensive resource for hotel owners, developers, and architects. "This possibly was the first time PVA had a published professional handbook for the industry," Beasley, Architecture Program director 1987–2000, said. The book, which received a Presidential Citation, was later updated and republished by McGraw Hill.

The '80s saw the development of accessible design standards and federal laws governing architecture, and the '90s brought about implementation. The landmark Americans with Disabilities Act, passed in 1990, affected virtually every aspect of design in corporate America and presented new opportunities for the Paralyzed Veterans of America to shape its implementation through the design standards. The Paralyzed Veterans of

America joined with the National Conference of States on Building Codes and Standards to develop a national program to help put the ADA into practice.

But architecture firms first had to understand the requirements of the ADA before they could follow them. In response to this need, the Paralyzed Veterans of America established the for-profit Paradigm Design Group in 1992. Paradigm offered fee-based consulting services to corporations and public institutions across the country.

An early consulting project was Baltimore's Oriole Park at Camden Yards. Through Paradigm's efforts, an adaptable seat, invented by Beasley, was integrated into the stadium. The Paralyzed Veterans of America holds a patent on this adaptable seat design. Though the program operated only four years before being inactivated, during that time Paradigm offered architectural advice on the design of numerous other sports facilities nationwide, including the 1996 Olympics in Atlanta.

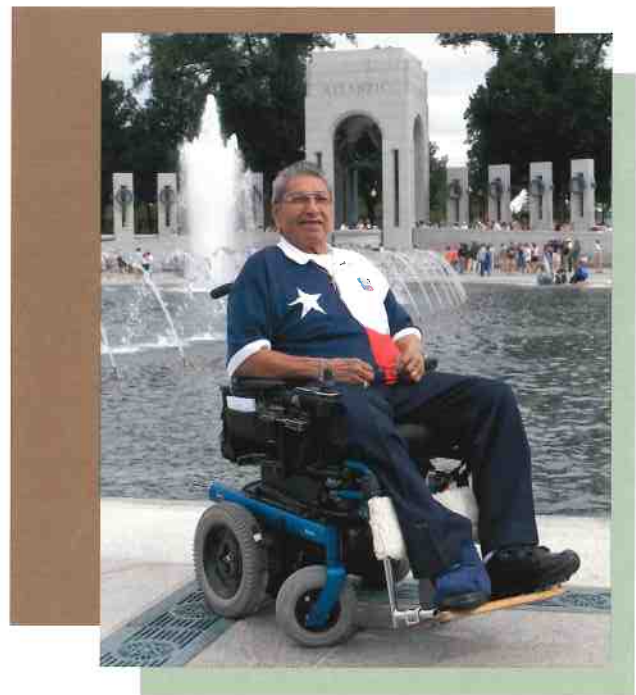
For more than three years, Paradigm staff conducted peer reviews of all new construction and renovation for the 1996 Olympics. Paralyzed Veterans of America architects reviewed plans for temporary and permanent facilities, operational and transportation planning, ticket sales policies, and volunteer training. These architects also developed a guide to the Games for visitors with disabilities and were on site in Atlanta during the event to answer questions and help solve last-minute problems. The Department of Justice hailed the Atlanta Olympics as the most accessible in the Games' history.

The issue of sightlines over standing spectators was raised during the Olympics, and the owner/operators were persuaded to provide wheelchair users with these comparable sightlines, as required by the ADA. Less than a year later, when an architectural proposal for a new sports arena in Washington, DC, did not include sightlines over standing spectators, the Paralyzed

Veterans of America pursued legal action to correct the design. Its success in that case effectively established a new national standard for wheelchair spectators at sporting events.

Public Places

The Paralyzed Veterans of America has consulted with designers and builders on hundreds of public projects, including national monuments. The Vietnam Veterans Memorial, built and dedicated in 1982, incorporated important recommendations that improved accessibility. Initially, the memorial was designed without accessible paths, only a lawn. The Paralyzed Veterans of America ensured that wheelchair-accessible walkways were installed at the right slopes and widths. In the early 1990s, Carlos Rodriguez, Paralyzed Veterans of America president 1970–72, represented PVA on the Korean Veterans Memorial Advisory Committee and helped ensure that the paths through the memorial were wheelchair accessible. The final plan of the World War II



PVA Architecture consults with designers and builders to ensure public spaces, such as our national monuments, are accessible. Pictured: PVA member John C. Martinez at the World War II Memorial in Washington, DC



With publication of *Accessible Home Design*, PVA provides design assistance to architects, builders, and homeowners.

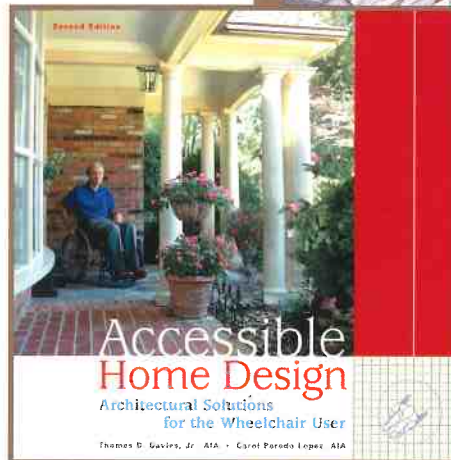
In 1998, the Paralyzed Veterans of America established a partnership with Bob Vila, host of "Bob Vila's Home Again," a nationally syndicated TV program on residential remodeling. After viewing a home-accessibility project in Roxbury, MA, on which Architecture had collaborated, hundreds of viewers sent email with questions about making their homes more accessible. As a result, Vila created a special section on his Web site to provide information, prepared by

the Paralyzed Veterans of America Architecture, about accessible home design.

Memorial also incorporated PVA's suggestions, including widening the pathways, recognizing the additional maneuvering space needed by wheelchair users. On any given day at the WWII Memorial, this generation's veterans, many of whom use wheelchairs, can easily access and view the tribute to their service.

Homes

Accessible housing issues have always been a priority. Staff architects offer assistance to members who may be building or modifying their homes. In 1998, Architecture published *Accessible Home Design: Architectural Solutions for the Wheelchair User*, which became a popular reference guide for wheelchair users and their families. The book was revised and expanded in 2006. The second edition includes color photographs and drawings illustrating attractive and innovative accessibility projects and provides pertinent technical information to aid the architect, the builder, and the consumer.





An important aspect in an SCI patient's rehabilitation is an accessible room that allows plenty of space in which a wheelchair can maneuver.

expertise to prove that the SCI center should not be reduced," Lopez said.

The architects at the Paralyzed Veterans of America research all aspects of SCI patient activities in order to optimize the design of these centers. For example, recessed elevator buttons can be difficult or impossible for someone with limited upper-body mobility to push. Such details are critical for the thousands of veterans receiving treatment and testing at these facilities.

SCI Centers

Liaison procedures developed between the Paralyzed Veterans of America and VA in 1986 set out specific steps for PVA to oversee construction of the Department's SCI centers. Numerous construction projects were planned, and the process ensured PVA's detailed involvement, on national and chapter levels, in every one from beginning to end.

"Within a few months of joining PVA in 1998, I was asked to redesign a proposed new tower for the San Juan VA Medical Center. It was my task to prove that the proposed VA project was not efficient, and that it was not necessary to reduce the number of SCI beds to meet their budget," said Carol Peredo Lopez, AIA, Architecture director.

"It was a monumental task to design a project of this scale, which typically takes a large architectural firm with many consultants to accomplish. With input from Kim Beasley and Tom Davies [both former Architecture directors], I was able to design a facility that VA adopted. The true accomplishment in that effort was that PVA—in a way no other organization could—was able to pool energy and technical

When VA dedicated a new SCI/D unit at the Louis Stokes VA Medical Center in Cleveland in 2001, Paralyzed Veterans of America architects analyzed how new technologies and modern medical practices could be effectively integrated into existing SCI facilities, such as Stokes. One outcome was the incorporation of a data-wiring system at patients' beds, enabling them to use a computer as a tool for occupational therapy programs or even as a platform for running movies. The Paralyzed Veterans of America is now back at Stokes, working to create specific criteria for long-term care patients.

Chapter Collaboration

When Paralyzed Veterans of America chapters become aware of accessibility issues in their communities, they often work with Architecture to resolve them. Their efforts promote ADA compliance in stadiums, arenas, movie theaters, and other local projects.

While working with New England Paralyzed Veterans of America (NEPVA), PVA architects provided suggestions during the design process of Gillette Stadium in Foxboro, MA. With technical support from Architecture, NEPVA offered its services and assumed the lead role of "watchdog" on behalf of the disability community. Architecture

reviewed the drawings and provided written comments to NEPVA, enabling NEPVA representatives to speak authoritatively on accessibility issues. The resulting venue eliminated obstructed sightlines and added premium accessible seating and other amenities, making Gillette Stadium a model of accessibility.

In 2003, Mid-South Paralyzed Veterans of America sent to the national office the architectural drawings of the new basketball arena for the NBA's Memphis Grizzlies. Architecture's technical review of the drawings revealed that the design fell short of accessibility requirements, thereby violating ADA. Paralyzed Veterans of America Architecture provided the technical assistance necessary to compel the design team to make extensive changes to the arena design, providing a more barrier-free experience and more variety and equitable seating locations for wheelchair users.

Toward a Barrier-Free America

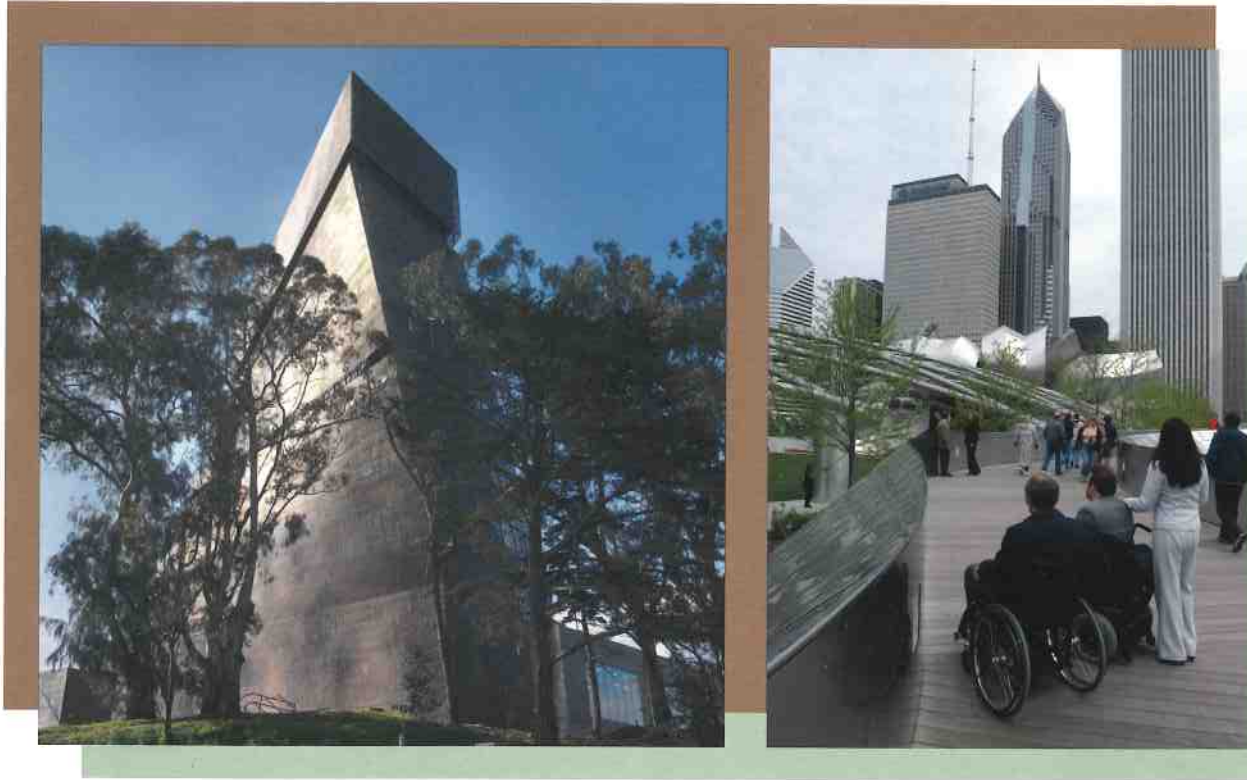
Annually since 2001, the Paralyzed Veterans of America has honored individuals for outstanding contributions toward a barrier-free environment.

"PVA architects work with designers, owners, and authorities to remove barriers and create accessible solutions across the country," Lopez explained. "Through our work, we become aware of other individuals who share our understanding that an obstacle is an injustice."

With this in mind, the Barrier-Free America Award was established. The award's pyramid shape symbolizes that all people are able to "go to the top" or wherever they want—if no physical barriers exist. Recipients have included Fong and Chan Architects, in recognition of the exceptional



Wheelchair users at Gillette Stadium enjoy "breathing space" behind them, and the seating areas are designed so that views are unobstructed even if a 6-foot or taller fan were to stand in front of them.



The Barrier-Free Award is presented annually by PVA to designers, owners, and authorities that strive to remove barriers and create accessible solutions across the country. Shown (left to right) are the 2006 winner, the de Young Museum in San Francisco, designed by Fong and Chan Architects, and the 2005 winner, Chicago's Millennium Park, designed by Edmund K. Uhler, FAIA.


accessibility of the de Young Museum in San Francisco; Edmund K. Uhler, FAIA, for the master plan of Chicago's Millennium Park; Frederic Bell, FAIA, for his role in the redevelopment of Lower Manhattan; Cesar Pelli, FAIA, the architect of Ronald Reagan Washington National Airport; and Bob Vila, for promoting accessible design through his television show and Web site.

In addition, PVA architects promote the adoption of appropriate and uniform accessibility standards and codes as part of ongoing work with the American National Standards Institute (ANSI). The Paralyzed Veterans of America had substantial input into new ANSI standards strengthening the most widely used model accessibility building-code regulations.

Team Effort Equals Success

PVA Architecture is unflagging in its commitment to design solutions that enhance accessibility in

the built environment: solutions addressing all sectors of the population and focusing on quality-of-life issues that include home, work, health care, and recreation; residences that allow owners to stay at home longer as they age; quality community and health-care facilities that offer maximum independence while providing a continuum of care; work environments that increase employment opportunities; and accessible educational, cultural, and recreational facilities that contribute to full participation in the community. Architecture continues to advocate these concepts through articles, books, and lectures with the vision of creating a built environment that truly includes all people.

"PVA is a national leader in the quest for a barrier-free environment," Lopez said. "We participate in key initiatives nationwide across the public and private sectors in order to one day see our mission fully realized." 

PATTERSON GRISSOM

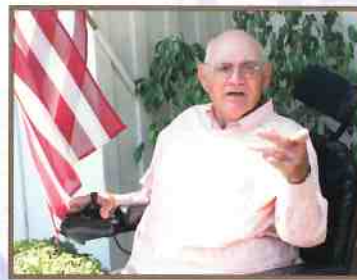
Patterson Grissom was serving in the Army's Third Infantry Division in 1944 when a bullet injured his spinal cord. The bullet went completely through his body, and he was left a paraplegic. He and other veterans with similar injuries spent weeks on their backs during recovery at Bushnell General Hospital in Utah. Eventually they were able to use wheelchairs, and they began to spend a lot of time, he said, in "bull sessions."

"We got to talking about what would happen to us. Life seemed to be going on in one way or another," he said.

A group of bilateral leg amputees at Bushnell had formed an organization and were pushing for new prostheses, artificial limbs, ways to better their lives. They were getting a lot of press, and the paralyzed veterans noticed. "We thought, well, we're in these rickety wheelchairs; there might be something better. We should organize. Based on the amputees' bylaws, Fred Smead, one of the paralyzed vets, drew up a set for us. Later, once we'd all been transferred to Birmingham (CA), we created the Paralyzed Veterans Association."

With patients continually being transferred between hospitals, the word spread, and like-minded associations formed around the country. But there were many challenges ahead for these veterans, who still, for the most part, were resigned to life in specialized hospitals. Public awareness was heightened with *The Men*, a film about paraplegic war veterans and their struggles and triumphs. Filmed in large part at the Birmingham facility, it featured many PVA members as extras, including Grissom.

"I thought the script was quite good, very realistic about what we were going through,"



he said. "It wasn't a documentary but it showed us guys in wheelchairs doing rehab, playing basketball or water polo. It changed the way people thought about paraplegia."

When the movie was released in 1950, Grissom was PVA president. He had by then witnessed a major victory for SCI veterans, the Paraplegic Housing Bill, entitling them to federal assistance in acquiring suitable accessible housing. He lives today in California, in a house VA helped him build. Few of his peers from those days remain.

"All of us who had been at the Birmingham hospital, we got to calling each other SOB—Survivors of Birmingham. Besides me, there are only a couple of SOB's left. I'm 81; my dad made it five months short of 100. You just never know; I've learned that you just have to take it as it comes."

Grissom may have learned to take life as it comes, but he and his peers at Birmingham were among the first to take up the fight on behalf of paralyzed veterans. He believes the organization has satisfied the intentions of PVA's founders. "I think our growth and impact has been phenomenal in legislation and medical research, in treatment and care of spinal cord injured...if I say so myself, I think we've exceeded their expectations."

Many Returns

The many programs and services provided by the Paralyzed Veterans of America are funded primarily through a national direct-marketing program of voluntary contributions from 3.5 million Americans as well as gifts from other generous supporters and corporations. The organization's loyal following consists of more than 18 million donors across the United States.



Air Force veteran (1945–1946) Bill Campbell is one of those generous supporters, who reasons: "These guys in wheelchairs—who's going to take care of them if PVA doesn't?"

Like Campbell, millions of Americans each year contribute to the Paralyzed Veterans of America to demonstrate their gratitude for the sacrifices our nation's veterans have made to protect our

In 1971, its 25th year, the Paralyzed Veterans of America received a congressional charter as a nonprofit national veterans service organization. Pictured: (left) Carlos Rodriguez, PVA president.



freedoms. Most monetary donations come in small amounts, in response to direct-mail appeals. Other members and friends provide support through their estate plans—e.g., a bequest or a charitable annuity naming the Paralyzed Veterans of America as beneficiary of a life insurance policy. Corporations, individuals, and organizations donate money and in-kind services as sponsors of PVA events. And many important donors give

generously of their time, serving as volunteers at national and chapter levels.

Each donor strengthens the Paralyzed Veterans of America and its ability to provide future service to members and others with SCI/D. Its accomplishments are a testament to the generosity and support of its many donors.



Iraqi veterans (L-R) Johnnie Williams, Ken Dixon, and Jason Wittling and family members at Arlington National Cemetery on Veterans Day 2003.

The Development Program—consisting of the Direct Marketing, Individual Giving, and Focused Fundraising departments—began 23 years ago when the organization hired its first full-time development professional. The program sought to raise funds at the lowest possible cost, while adhering to professional standards and ethics. It is responsible today for raising funds to support all Paralyzed Veterans of America initiatives and services. It also assists PVA chapters, which have their own special programs that depend on private support.

A Shaky Start

Poor financial health in the early 1950s prevented the young organization from growing and expanding its programs and services. The initiation of a greeting-card program in 1958 provided the financial boost needed to expand. Twice a year, boxes of cards were sent out in PVA's name from a greeting card company. An accompanying brochure described the Paralyzed Veterans of America and solicited monetary donations. This program started out slowly, but with steady growth and planning, it became huge.

Financial woes emerged again in the 1960s. The organization's total income in 1964 was projected to be only about \$60,000, all but a few thousand dollars coming in through the greeting card program.

Wayne Capson, national president from 1968 to 1970, recalled the severity of the situation, noting that in 1968 research had but a \$300 budget—basically postage. "Everything was being cut back because the funds were just real tight," he said.

Because of the importance of fundraising, PVA decided to focus much more high-level attention on this critical area. PVA leaders decided the organization should set up and manage its own fundraising program. The resulting PVA/EPVA, Inc. (PEP), in Wilton, NH, produced its first fundraiser: the 1973 Christmas card line. The venture was successful for many years, allowing PVA to provide more services in a professional manner.

You've Got Mail

For the first 20 years, direct mail—in which donors and prospective donors receive inexpensive premiums (return-address labels, greeting cards, calendars, etc.) in their mailing pieces—accounted for virtually all the revenue used to fund Paralyzed Veterans of America's services. Development's direct mail program has been the mainstay of PVA's revenue since the late 1950s. According to Nichole Krieger, director, Direct Marketing, "Direct marketing raises 89 percent of our overall fundraising revenue. We do this primarily through our direct-mail programs."

The premium program (sending out cards, calendars, labels, notepads, and other items to nearly 3 million donors monthly) dates to around 1958. The nonpremium program (appeals for donations to nearly 400,000 people monthly) has been in action since 1987.

Since 1980, when PVA created a donor database, the organization has received more than 124 million gifts exceeding \$1 billion from patriotic Americans. "This is gross revenue—what we take in, not what we are able to spend," Krieger explained.

To combat the challenges of other competing causes, mailbox clutter, and the growing cost of fundraising, the Direct Marketing team continually looks for alternative methods. "Our program is trying to move toward corporate gifts, more

individual high-dollar gifts, and to alternative media, such as TV, radio, and the Internet," said Mark Dowis, associate executive director, Development and Marketing. "PVA also recognizes the changing needs of our donor culture. We're facing a more savvy future donor base that doesn't respond as well to direct mail."

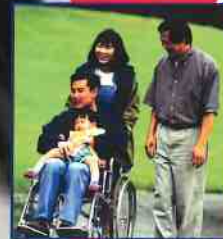
New Ventures

New Ventures is a relatively new program created in order to boost revenue by looking at programs outside of direct mail, according to Chun Gee, associate director of New Ventures. Among these are TV, Internet, radio, and outdoor advertising



Generations of Service to America's Veterans:

Paralyzed Veterans of America Department of Veterans Affairs



The National Veterans Wheelchair Games co-presented by PVA and VA, the largest annual wheelchair sports event in the world.

This space is provided by WMATA as a public service. WMATA does not endorse any service, event, or program described in this message.

Metro train and bus signage celebrated the generations of service to our veterans in this campaign jointly sponsored by PVA and the Department of Veterans Affairs.

(billboards). Interactive marketing online is one key area of success. It is projected to continue to grow at least at the same pace as last year.

"PVA will continue to embrace an emerging shift to online charitable gifts by focusing on growing the constituent email file, sending regular communications, maintaining compelling content on the Web site, and issuing interactive email appeals," Gee said. "By engaging people online, we hope to create 'value-added' with up-to-date information about the Paralyzed Veterans of America, offer new products and services exclusive to the online community, and target a diverse pool of future donors."

Individual Giving

"Individual Giving is about relationship-building," said David Fanning, director, Individual Giving (IG).

"Whether it is stewardship by the Planned Giving Committee, door-opening by the Advisory Committee, and/or the staff's cultivating, soliciting, and stewarding the donors and prospects, IG is constantly working to secure major and planned gifts."

According to Fanning, since 1999, the program has secured more than \$30 million in low-cost revenue for the Paralyzed Veterans of America and its related foundations and chapters. "These gifts range from outright cash up to \$250,000 and estate gifts, including nearly \$5 million for the Paralyzed Veterans of America, nearly \$1 million for the PVA Research Foundation, and almost \$1.5 million for the chapters," Fanning said. "Moreover, we are constantly aware and grateful for the hard work and relationship-building our colleagues in Direct Marketing have accomplished through the mail. Without exception, all IG donors began their relationship with PVA as direct-mail donors."



PVA's Web site and interactive email appeals are future tools that will be used to offer new products and services to PVA supporters.

Over the past 12 years, IG has moved from providing a very small portion of Development's net income to generating more than 10 percent in 2005. This dramatic increase has been most evident in the years since 1999, when IG's unrestricted net income grew from \$863,756 to more than \$6 million in FY 05.

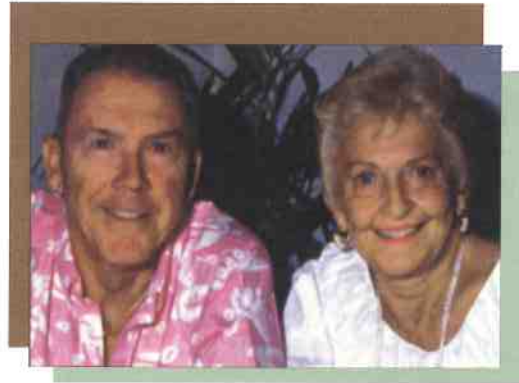
In 2000, Development initiated a special wills and bequests program. It provided guidance and planning tools for members and supporters who wished to prepare their wills and perhaps include the Paralyzed Veterans of America as a beneficiary. The PVA Legacy Circle recognizes the individuals who do so.



Lucille Farlow, a generous supporter and a member of the Legacy Circle, reflects the thinking of many of these donors: "It is through my contributions that I can show my support of our veterans, especially those with spinal-cord injuries received as a result of their incredible service and sacrifice."

"Contributions from our estate-gift program have increased significantly," Fanning said, "along with outright cash contributions of \$250 or more. Expense control and a steady supply of five- and six-figure estate gifts have helped us reduce our costs to raise a dollar from nearly 60 cents in 1998 to less than 20 cents in FY05. IG is doing more with less."

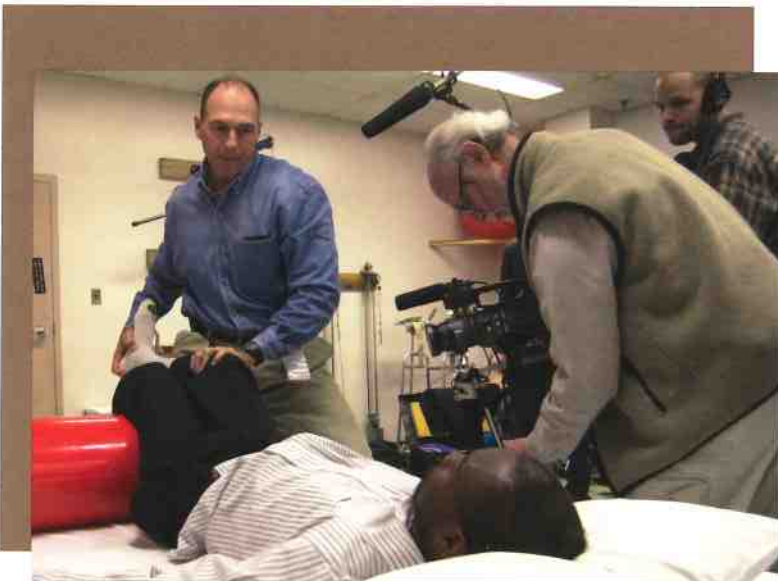
Gifts in honor or memory of individuals also prompt donors to consider the Paralyzed Veterans of America in their estate and/or tax planning. In memory of her husband, Col. Rodney E. Houghton, a member of the Air Force Air-Sea Rescue, Arlene Houghton established a generous charitable gift annuity in 2005. After Col. Houghton had a serious heart attack at age 46 that left him 80 percent permanently disabled, PVA national service officers at a VA medical center advised



Col. Rodney E. Houghton and wife, Arlene

Mrs. Houghton on the steps to take to ensure that the colonel received his benefits. Years later she recalled that assistance. "With all the charitable organizations, none comes more to the top of the list than PVA," she said. Her gift annuity not only provides income for the remainder of her life but is also a lasting tribute to her husband.

Member Fritz Krauth sustained a spinal cord injury while serving as an aviator for the U.S. Navy. Before his death in 2002, he made a \$500,000 gift to support research initiatives approved by the Research Foundation. The Krauth Memorial Fellowship is awarded to the top-ranked fellowship applicant each year.



Public service announcements, produced by PVA Communications, help build awareness of PVA and its programs and services for veterans with SCI.

The Research, Education & Clinical Practice Guidelines program launched a capital campaign in 2002, which to date has raised about \$5 million from individuals, foundations, and corporations dedicated to research for a cure or to improvement of veterans' quality of life through education and clinical practice guidelines.

The IG program will be a mainstay of PVA's future fundraising. "As America faces some dramatic demographic changes over the next two decades, IG is poised to ensure PVA continues



Invacare Corporation has supported the National Veterans Wheelchair Games since the beginning. Corporate donors are essential to PVA's success.

supply companies, pharmaceutical companies, and other corporations are eager to support the competitive and recreational activities for the hundreds of veterans which participate in this exciting annual event. Corporate donors, which provide funds and/or in-kind services and equipment, are extremely loyal. Invacare Corporation has been on board since the beginning, along with UPS, Xerox, The Roho Group, 3M, Pfizer, Anheuser Busch, Johnson & Johnson, and Independence Technology, as well as the DeGasperi Family Foundation and The Budin Family, have been long-term supporters as well.

to receive its fair share of generous Americans seeking to invest in honoring the service of our veterans," Fanning said.

Focused Fundraising

In 1985, when the growing size and complexity of the National Veterans Wheelchair Games challenged the VA medical centers hosting the event, PVA became a partner, providing financial and logistical support and initiating a program to enlist corporate participation, a major factor in the Games' growth. Development and Marketing has found that wheelchair manufacturers, medical

"Corporate Marketing approaches businesses who have shown interest in veteran or disability issues," Dowis said. "We educate them about PVA's mission and identify areas of possible involvement."

Thanks to dedicated and generous corporate and individual donors, the Paralyzed Veterans of America has evolved from a small, grass-roots organization struggling to keep itself united and financially alive into a financially secure professional advocate for its members, all veterans with SCI/D, and all people with disabilities. ♿

PETER AXELSON

Peter Axelson was at the United States Air Force Academy in 1975 when he injured his spinal cord in a climbing accident. After rehabilitation, he received an issue of *Sports 'n Spokes* magazine and learned how to stay active physically. He later began a career as a researcher and a developer of adaptive equipment for people with disabilities, founding Beneficial Designs in 1981.

"Physical activity for a person with a spinal cord injury is essential. There are now many studies that show that active people in wheelchairs have fewer kidney infections, fewer skin breakdowns, and other medical complications, as well as greater self-actualization and positive emotions. Many Beneficial Designs devices, including hand controls for manual transmission vehicles, a piano pedal pusher operated by the abdominal muscles, and an adaptive canoe seat, have been inspired by my desire to reestablish physical, intellectual, and spiritual balance in my life," he said.

"My love of outdoor recreation has led us to specialize in the development of adaptive recreation equipment, including mono-skis, cross-country snow skis, a wave ski for surf kayaking, and ultralight aircraft modifications."

Beneficial Designs also develops technologies to improve the quality of daily life for people with disabilities. This includes designing, building, and testing innovative wheelchairs, ergonomic wheelchair back support systems, and low-impact push rims. The company also publishes information so wheelchair users do not necessarily limit their activities only to familiar environments.



"Our wheelchair training guides, supported by PVA's Education Foundation, teach manual and powered wheelchair users how to access diverse environments safely," he explained. "Our Universal Trail Assessment Process offers access information about outdoor recreation trails. This, in turn, has led to designing devices and methods to objectively measure surface firmness and stability."

Axelson has been on the board of the PVA Research Foundation for 27 years. The board is entrusted with the funding decisions based on review by a prominent panel of experts who comprise the Scientific Advisory Board. To be funded by PVA, a project must first have merit, and it must be relevant to the goal of improving quality of life for PVA members and all of those with SCI.

"The PVA Research Foundation was the first to fund my work at Beneficial Designs, and as a result of this investment, we have received at least 10 National Institutes of Health grants since. PVA was there for me when no one else was," Axelson said. "I support the work of PVA and the Research Foundation in seeking treatments and cures for SCI. I believe these treatments will come. But I'm not waiting around for them."

Those Who Fought and the Lawyers Who Fight for Them

In 1803 the Supreme Court case *Marbury v. Madison* established the principle of “judicial review,” and the important role courts would play today in defining the law. However, it took 185 years before judicial review became available for Board of Veterans’ Appeals (BVA) decisions regarding veterans benefits.



The Paralyzed Veterans of America and other veterans service organizations worked to achieve this much-needed judicial review, and in 1988 the Veterans’ Judicial Review Act established the U.S. Court of Veterans Appeals, now the U.S. Court of Appeals for Veterans Claims (Veterans Court), as an independent Article I Court to review final decisions of the BVA.



PVA member James A. Gaddis was the 1,000th case taken by the Veterans Consortium Pro Bono Program. Also pictured are former Sen. Robert Dole, who was one of Mr. Gaddis's legal representatives, and Dave Isbell, who served as Executive Board chairman of the program from 1992–2004.

This legislative victory did not end the Paralyzed Veterans of America's commitment to judicial review, however. At the organization's convention following the act's passage, the Board of Directors authorized the position of deputy general counsel, with a view toward refining the organization's representation of veterans and providing representation for veterans before the federal courts.

Lawyers in the Office of General Counsel (OGC) now play a major role in ensuring that Paralyzed Veterans of America members, as well as other veterans, obtain the benefits to which they are entitled. As resources permit, free legal representation in benefit claims is available through two programs offered by PVA's Office of General Counsel: the Veterans

Appeals Litigation Office (VALO) and the Veterans Consortium Pro Bono Program.

Veterans Appeals Litigation Office

Established in 1991, the Veterans Appeals Litigation Office has provided representation to hundreds of members and other veterans before the Veterans Court. The majority of cases decided by this court result in “remand,” that is, return to the BVA or a VA regional office for further consideration. VALO attorneys then assist Paralyzed Veterans of America service or appeals officers to ensure that the issues raised on remand are properly handled.

Claims decisions arising out of cases litigated by the Paralyzed Veterans of America often result in groundbreaking law with wide-ranging impact for PVA members—and the veterans community at large. In 1995, the Paralyzed Veterans of America and other veterans organizations joined to present an amicus or “friend of the court” brief to the U.S. Supreme Court in the case *Brown v. Gardner*. This was the first appeal of a decision by the Veterans Court heard by the U.S. Supreme Court. This pivotal case overturned a 70-year-old VA regulation and made it clear that veterans who sustain further disability as a result of VA medical care may be entitled to additional disability benefits. Paralyzed Veterans of America General Counsel Bill Mailander assisted Gardner’s lawyer and wrote a portion of the brief.

Two years later in *Allen v. Brown*, the Veterans Court ruled that veterans are entitled to secondary service connection for an *increased level of disability* when a service-connected disability aggravates an otherwise nonservice-connected disability. Previously, VA would grant secondary service connection only if it were shown that the service-connected disability caused another disability or disease.

In 1998, in *Collaro v. West*, Michael Horan, current deputy general counsel, successfully

argued before the U.S. Court of Appeals for the Federal Circuit that a veteran’s lawyer should be allowed to present all pertinent legal arguments regarding a claim even when it had not been fully developed before VA. This case was significant for veterans seeking benefits as well as those seeking judicial review for denied claims.

Splane v. West focused on the BVA’s action to obtain a VA general counsel opinion in a case the Veterans Court had remanded. Linda Blauhut, current associate general counsel, sought review in the Federal Circuit. In 2000 the Federal Circuit ruled it had jurisdiction to review the VA general counsel opinion and deciding it was contrary to statute.

In *Kilpatrick v. Principi* in 2003, the Federal Circuit affirmed a Veterans Court decision holding that veterans disabled as a result of VA treatment and otherwise qualified are eligible for the specially adapted housing grant. Congress then amended the law to make it clear that veterans like Kilpatrick are entitled to the automobile and adaptive equipment grants, as well.

In 2006, in one of the most important cases ever in the field of veterans law, *Mayfield v. Nicholson*, the Federal Circuit accepted the argument put forth by Horan and ruled that VA must provide claimants with a detailed notification of the information or evidence it needs from them in order to substantiate their claims for VA benefits. Before *Mayfield*, the BVA and the Veterans Court could combine several non-VCAA notices, issued to a claimant over a period of many months or years, to support their conclusions that VA provided adequate VCAA notice to the claimant. This landmark case applies to every Paralyzed Veterans of America member, disabled veteran, dependent, or survivor who has a claim pending before VA or who will ever file a claim with VA. Hundreds of thousands of claimants will benefit from the *Mayfield* opinion.

VA Rulemaking

Review of VA rulemaking also can have far-reaching effects on the lives of veterans. For example, in a Paralyzed Veterans of America–petitioned review of the restrictive nature of VA procedures governing dependency and indemnity compensation (DIC) for surviving spouses of deceased veterans, the Federal Circuit Court found in part that VA had not adequately addressed the grounds for reopening disability claims. This court determined that VA had failed to comply with its earlier directions in reconciling its rules, so it directed VA to pursue further rulemaking proceedings on an expedited basis.

In another case, after input from the Paralyzed Veterans of America OGC, VA amended proposed enrollment regulations that would have placed many Paralyzed Veterans of America members at the bottom of the list for VA health care. PVAs heavily researched commentary persuaded VA to change its rules and ensure needed care for many vets with SCI/D.

Pro Bono Program

When veterans won the right of judicial review of denied benefit claims, no one anticipated that more than 80 percent of veterans



Members of PVA's Office of General Counsel: Brian Robertson, Michael Horan, and Linda Blauhut

seeking case reviews by the U.S. Court of Appeals for Veterans Claims would not be able to obtain representation. Though these veterans may have had a meritorious claim, an appellant acting alone faces a formidable adversarial system in which VA counsel staunchly defends the agency's denial of benefits.

The court took action to correct this imbalance by creating a pro bono program to help ensure that appellants have counsel before the court. In May 1992, proposals were solicited to establish and operate a pro bono program. The American Legion, Disabled American Veterans, National Veterans Legal Services Project (now Program), and the Paralyzed Veterans of America offered their combined resources to form the Veterans Consortium. As advocates for veterans for many decades, these groups have expertise in veterans law, policy, and VA practices. In its first decade, the Pro Bono Program screened more than 5,000 requests for assistance. More than 2,400 veterans obtained free legal counsel on their cases before the court.

David B. Isbell, former president of the District of Columbia Bar and chairman of the Executive Board of the Pro Bono Program from its inception in 1992 until 2005, observed, "By reason of the Veterans Consortium Pro Bono Program, the United States Court of Appeals is the only federal appellate court of which it can be said that every appellant who has a substantial claim and who wishes legal representation in pursuing that claim on appeal is provided such representation."

The Veterans Consortium Pro Bono Program recruits and trains volunteer lawyers in veterans law and Veterans Court procedures. It can refer

evaluated cases to these lawyers to handle without cost to the appellants. PVA lawyers have mentored more than 650 volunteer lawyers. The consortium recently extended its services to include representation before the U.S. Court of Appeals for the Federal Circuit as well as the Veterans Court.

PVA plays a major role in the Case Evaluation Placement Component (CEPC), which assigns eligible cases to volunteer or Direct Representation Component lawyers. PVA oversees CEPC's operations in reviewing cases, determining eligibility, selecting cases with viable legal issues, preparing legal memoranda, and informing veterans of the results of their case evaluations.

The concept works, and works well," said Brian Robertson, CEPC director. "The program's volunteer lawyers regularly prevail in more than 75 percent of the cases—an amazing result for an appellate litigation program."

The pro bono program is a win-win situation for veterans and attorneys. Veterans receive competent legal representation, and young lawyers obtain practical experience before a federal court. In 2004, Meredith Martin Addy, a patent attorney in the firm of Brinks Hofer Gilson & Liono and former Federal Circuit law clerk, represented a World War II veteran's widow in a claim for dependency and indemnity compensation. The widow had relied on VA to draft her claim, and VA had failed to specifically consider the most relevant statute. Yet the U.S. Court of Appeals for Veterans Claims (CAVC) dismissed the appeal without substantive review without regard to VA's failure to perform its responsibility. The CAVC would not review VA's failure to fulfill its duty to assist.



Addy and her colleague reviewed details of the 50-year-old claim and drafted the appeal to the Federal Circuit. Following a settlement at the Federal Circuit, Addy continued to assist the widow before VA, where the case was eventually favorably resolved. Addy said the reward for her was knowing that the widow finally received her owed benefits.


Beyond the Law

PVA's reach often extends beyond veterans law, sometimes as an *amicus curiae* [friend of the court] in legal matters important to PVA. Over the years, PVA has filed briefs in cases involving patent infringement, interpretation of the ADA, and veterans' employment rights.

An especially important victory for PVA occurred in 1998 when the U.S. Supreme Court declined to review a lower court decision in *Abe Pollin v. PVA*. This preserved the favorable decision of the D.C. Circuit Court of Appeals in *PVA v. D.C. Arena*, which was that the regulations implementing the ADA required arena owners to provide wheelchair areas with lines of sight unobstructed by standing spectators. This decision and other successful actions the Paralyzed Veterans of America has been involved in enabled the U.S. Department of Justice to enter into a consent order binding the nation's largest architect of such facilities to design facilities in compliance with the principles

established by the Paralyzed Veterans of America in its lawsuit.

In addition, through outreach to the legal community, the Paralyzed Veterans of America enhances the visibility and attractiveness of the practice of veterans law. The Paralyzed Veterans of America has awarded scholarships to law students who agreed to represent one veteran per year for three years before the Veterans Court. PVA sponsored a veterans law scholar to regularly update analysis of the Veterans Court's jurisprudence. A DVD on veterans law was produced and distributed to law schools nationwide. The Office of General Counsel sponsors an annual national legal writing contest for law students and practitioners and publishes two law newsletters: *Tommy*, for the Veterans Law Section of the Federal Bar Association, and *SOAR* (*Service Officer Appeals Report*) for the Paralyzed Veterans of America's network of service officers.

"We will continue to focus on meeting the needs of our clients as well as striving to facilitate the achievement of PVA's business goals," Mailander said. "I am particularly proud of our efforts in the field of veterans law, where PVA lawyers are on the front lines and have significantly enhanced the law and the lives of those who depend on its full and fair application." 

RORY A. COOPER, PhD

Engineer Rory Cooper has been a member of PVA since 1980. Active in its sporting programs, funded by the Research Foundation, published by *PN*, Cooper has experienced the range of benefits that comes from PVA membership. "No other organization has a greater positive impact on my personal and professional life than the Paralyzed Veterans of America," he said.

When Cooper, a high school and Army track athlete, first learned about wheelchair sports and the emergence of ultralight wheelchairs, he had "a renewed hope" that he might once again compete. "Right away I began training in my 'depot' style wheelchair, which quickly proved unsuitable for the task. I was fortunate to have a mechanically inclined family and began to tinker with new racing wheelchair designs."



Upon earning a doctoral degree in engineering, Cooper accepted a faculty position in the biomedical engineering program at Cal State Sacramento. PVA provided funding to develop test equipment and to conduct tests in support of the wheelchair standards.

He became involved with the PVA Research Foundation and later became a member of its board of trustees. When he relocated to the University of Pittsburgh and was asked to be a founding member of the Department of Rehabilitation Science and Technology, PVA awarded the new department its very first grant, providing a foundation for future research and development. PVA helped start the Human Engineering Research Laboratories, a joint venture between VA, the University of Pittsburgh, and the University of Pittsburgh Medical Center. PVA and its Pennsylvania chapter, Keystone PVA, have supported HERL each year for more than 10 years.

"I have repeatedly said that 1 dollar from PVA is worth 10 federal dollars, given the flexibility and risk that PVA is willing to take before the research and development is ready for a federal grant," Cooper said.

"In part because of PVA's unwavering support, HERL was awarded a VA Rehabilitation Research & Development Center of Excellence grant in 1999, which was renewed in 2004, and a NIDRR Model Center for Spinal Cord Injury."

PN publishes the results of HERL studies, and the Games have become an important avenue for HERL research. "PVA has provided invaluable support for our research at the Games. Also, as wounded soldiers returned from Iraq and Afghanistan, HERL consulted with the Walter Reed Army Medical Center, including hosting workshops on translating research into clinical practice. PVA has supported these workshops financially and programmatically," Cooper said.

In 2004 the University of Pittsburgh and the locally based FISA Foundation agreed to endow a chair with PVA. Cooper was the inaugural chair holder. "The dividends from the endowment help to provide support for research, development, outreach, and educational activities," he said. "Through its generosity, PVA will have its name associated with the University of Pittsburgh in perpetuity, thus supporting generations of future research."



Since its founding by a handful of courageous veterans, the Paralyzed Veterans of America has pursued a vision: to accomplish all it can to enable veterans with spinal cord injury or dysfunction (SCI/D) to lead full, productive lives.


The path to change is often long and difficult. We have seen significant victories in the legislative arena, and we will always petition the government for the full rights and privileges guaranteed by the Constitution and our laws. But making a difference in the lives of our members frequently is the result of bringing to light the simple fact that even with a debilitating injury, a full life is indeed possible. The myriad programs and services PVA offers ensure the fullest participation in society by all of our members.

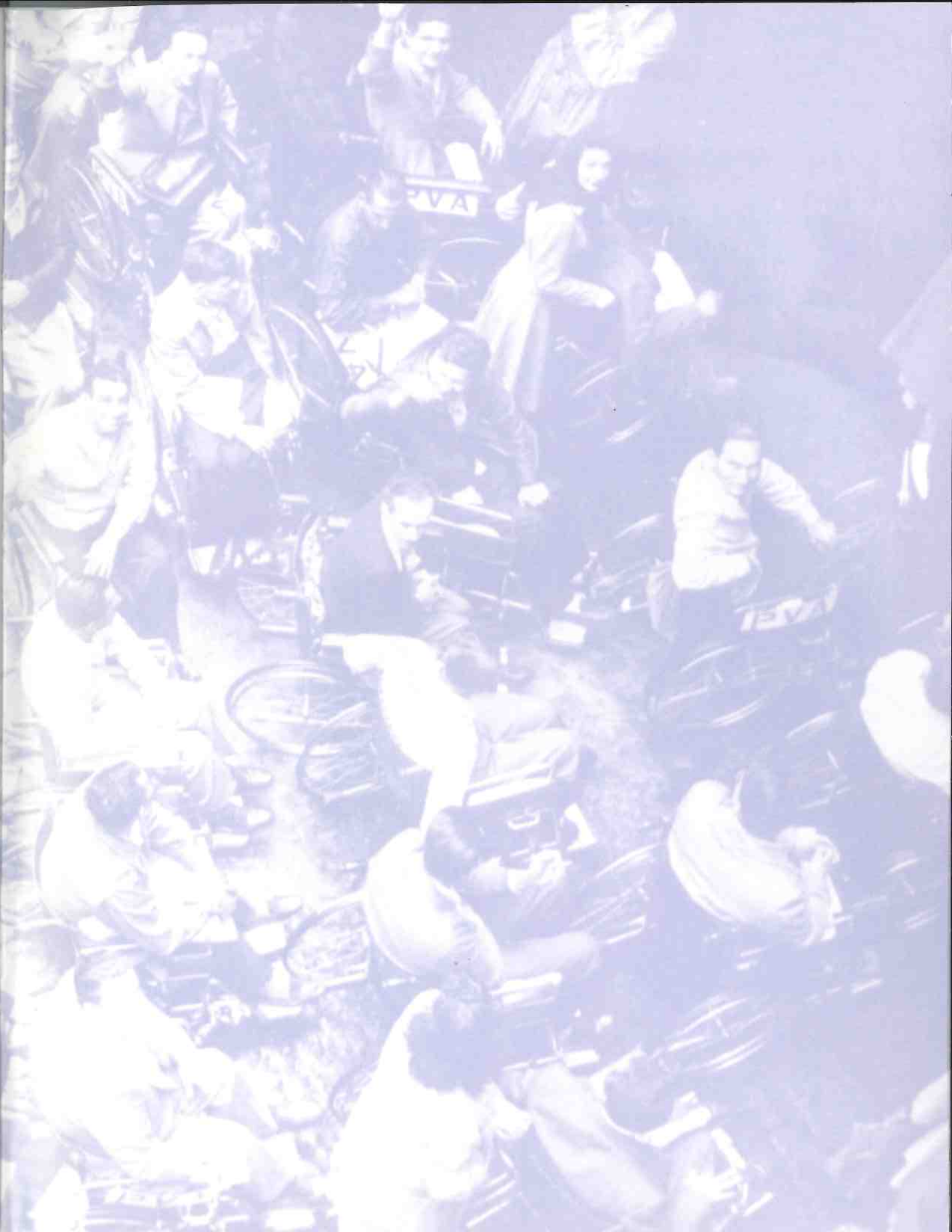
Our greatest hope is that one day there will be a cure for paralysis. Our commitment to those with SCI/D includes a staunch dedication to supporting research for a cure and for treatments that can improve lives until there is a cure. PVA-funded researchers are making new discoveries every day. Their commitment is as steadfast as ours, and already our members and the disability community have benefited from their work.

For the past 60 years, the Paralyzed Veterans of America has led the way in ensuring that the full range of needed health care is available to our members. Yet, as much as we have accomplished, our work does not end. Sadly, every day young men and women return home with injuries sustained in Iraq and Afghanistan. We know that since these conflicts began, more than 60 servicemen and -women have sustained

spinal cord injuries, and many more remain unaware of how PVA can assist them. Taking care of our members, ensuring that they receive the full range of medical care and benefits from the Department of Veterans Affairs, will always be our first priority.

In recent months, PVA has assumed an even larger role of assistance. Floods, tornadoes, and hurricanes are frightening realities in all of our lives. And for those with SCI/D, replacing specially built homes, accessible vehicles, or adaptive equipment cannot happen fast enough. When cities in the Midwest and Northeast were hit with torrential rains and flooding and hurricanes devastated the Gulf Coast region, PVA responded with emergency relief funds to help our members recover as quickly as possible. We are committed to being there for our members in all times of need.

The strength of the Paralyzed Veterans of America is and always has been its members—from the founding fathers to the approximately 20,000 men and women members today. And with their strength as our inspiration, we pledge the following: Wherever we see veterans with SCI/D in need of assistance, we will be there. This was the ambitious goal of the men who formed the first associations of paralyzed veterans and it is our continued focus. We will be there. 





PARALYZED VETERANS OF AMERICA



*Building
a Better
America*

